Health information sharing between education and health sectors for children in their early school years: principles, perceptions and potential

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“Mā te rongo, ka mōhio

Mā te mōhio, ka mārama

Mā te mārama, ka mātau

Mā te mātau, ka ora”

“Through perception comes awareness,

through awareness comes understanding,

through understanding comes knowledge,

and through knowledge comes well-being”

– Māori whakataukī (proverb)

Abstract

Background. Many of New Zealand's children are entering school with low oral language ability. Many are also experiencing health concerns that impact the development of academic skills critical to school success. Mitigating adverse impacts of poor health are likely to improve children's academic achievement and overall well-being. Early intervention is particularly necessary to improve outcomes for children who are experiencing significant health or learning challenges. Early intervention will allow targeted support so children can overcome challenges before they significantly fall behind their peers. However, sharing health information for early intervention strategies is often delayed, with the responsibility to share this information being placed solely on the caregiver. Teachers are thus unaware of the health profile of their classrooms and are unable to introduce early intervention strategies or support the whole child.

The extended capability for collaborative, multi-sector practice, along with the rise of digital systems, suggests a digital student health information sharing system (DSHISS) may facilitate sharing of student health information between health professionals and educators (Cunningham & Wodrich, 2006). A DSHISS may allow for earlier intervention, resulting in timely and targeted support that empowers children to overcome health challenges and reach their full potential. Despite the potential gains of a DSHISS, the real and perceived risks of such a system require significant buy-in from key stakeholders and must also consider the legal and ethical implications. It is essential to consider the appetite of teachers and parents and establish the support or opposition for sharing health information before implementing a DSHISS.

Aims. This doctoral research had three broad aims:

1. establish a health profile of children who enter school with known challenges for their school success and investigate the need for integration of health data in New Zealand schools;

2. understand teacher perceptions toward sharing student health information, including the perceived benefits and risks; and,
3. understand parent perceptions toward sharing student health information, including the perceived benefits and risks.

Methodology and Methods.

Three phases characterised this research. Using quantitative research methods, phase 1 established a health profile of 85 children entering school with low oral language ability, then utilised a convergent mixed method design to understand parent's beliefs on health information sharing. Quantitative data prompted participants to think about sharing health information, with qualitative data allowing participants to explain their answers and understand the drivers for their opinions. These findings informed the questionnaire development for phase 2 and 3.

Phases 2 and 3 utilised an explanatory sequential mixed methods design. Teachers (n = 26) and parents (n = 99) of 5 to 7-year-old children completed a questionnaire regarding their views of sharing student health information and the roles of key players within the education system. The questionnaire utilised quantitative research methods to look at the similarities and differences in views around health information sharing between schools and other demographic areas. In the second stage of each phase, teacher (n = 7) and parent (n = 10) participants attended a focus group session, utilising qualitative research methods, via thematic analysis, to clarify questionnaire findings and develop themes pertinent to considering a DSHISS.

Findings.

Phase 1 found that of children entering school with low oral language ability, 55% of participants expressed at least one concern with their child's health, with 29% identifying over

one health concern. One in five children had experienced asthma, eczema/dermatitis and ear infections in the past 12 months. Sixty-one percent of participants thought teachers should have access to student medical records, with 62% believing that consent should be given only when a request is made for health information to be released (rather than automatically at enrolment).

In phases 2 and 3, parents and teachers displayed generally positive attitudes towards sharing student health information giving similar explanations for their attitudes. The focus group thematic analysis identified four key themes:

1. *The roles within health and education need flexibility*: the roles of educators and parents must be flexible and reflective on community need to share health information to improve children's academic performance and holistic well-being.

2. *There are significant benefits to sharing student health information*: these benefits to sharing children's health information with educators include the ability to provide greater targeted and tailored support as well as safer learning environments.

3. *If sharing health information is done carelessly, there is potential for harm*: the risks of sharing health information include the potential for misuse and misinterpretation of health data.

4. *Taking a solution-focused, collaborative approach to implementation*: A range of strategies could reduce the perceived risks of health data sharing, including clear policies, practices, prioritizing trusting relationships between home and school, and limiting what data is shared.

Conclusion. The findings suggest that children who enter school with low oral language ability are experiencing health concerns that could result in these children missing out on further teaching that builds vital foundational learning skills for learning success. Yet, the majority of these children's parents would be happy to share health data with the child's teacher, which could lessen the impact of health issues on learning. By sharing health information, teachers

can offer targeted early interventions to children that consider both their oral language ability and health concerns. The findings from this thesis support the need to investigate multi-disciplinary approaches to health information sharing, especially given the frequent occurrence of health issues in children who enter school with a higher risk for educational challenges.

Parent and teacher participants were able to discuss their perceptions of sharing children's health information and the development of a DSHISS. They acknowledged that schools and teachers must reflect the needs of their community. Participants highlighted their perceived benefits by discussing the opportunity for triangulation with sectors outside education, more efficient and targeted early intervention in schools, and greater school safety. Conversely, participants considered the risks of sharing information, discussing fears of privacy and confidentiality breaches. Ultimately, participants recognised the potential for a DSHISS to have significant value if these risks are mitigated. Real-time access to health information and tailored support strategies could have a considerable impact on reducing adverse effects on children's school success from health concerns. Participants desire to minimise risks associated with student health data sharing highlight the value of the perceived benefits.

While the New Zealand education sector is beginning to take a child-centric approach in the classroom, there is room for improvement, especially around how to manage health in schools. This research highlights the potential for integration of health in schools and justifies greater cross-sector collaboration. Through facilitation from digital technology, greater integration and cooperation between health and education sectors could see the improvement of both health and education outcomes. The extent of this improvement, along with the legal frameworks surrounding information sharing, requires future research. However, the general openness of participants in this study towards a DSHISS calls for further exploration.

Acknowledgements

"Ehara taku toa, he takitahi, he toa takitini"

"My success should not be bestowed onto me alone,

as it was not individual success but success of a collective"

– Māori whakataukī (proverb)

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List of Abbreviations

ABS	A Better Start
ADHD	Attention Deficit Hyperactivity Disorder
B4SC	Before School Checks
CBPA	Computer-Based Phonological Awareness Assessment
CDHB	Canterbury District Health Board
CELF-P2	Clinical Evaluation of Language Fundamentals – Preschool 2
CMR	Component model of reading
COREQ	Consolidated criteria for reporting qualitative research
COVID-19	2019 novel coronavirus disease
DHB	District Health Board
DSHISS	Digital Student Health Information Sharing System
ECE	Early Childhood Education
ERHEC	The Educational Research Human Ethics Committee of the University of Canterbury
ERMS	Electronic request management system
FET	Fishers Exact Test
FSCS	Full-Service Community School
GP	General Practitioner (Family Physician/Doctor)
HIPAA	Health Insurance Portability and Accountability Act of 1996
HIPC	Health Information Privacy Code 1994
IDI	Integrated Data Infrastructure
InterRAI-HC	Home Care International Residential Assessment Instrument
IRD	Inland Revenue Department
IT	Information Technology
ITS	Information Technology Systems
NHI	National Health Identifier
NZ	New Zealand

NZDFF	New Zealand Data Futures Forum
OM	Otitis media
PA	Phonetic Awareness
PC	Office of the Privacy Commissioner
PIRLS	The Progress in International Reading Literacy Study
SDoH	Social Determinants of Health Model
SDQ	Strengths and Difficulties Questionnaire
SEMH	Social, Emotional, and Mental Health
SES	Socioeconomic Status
SWA	Social Well-being Agency
SLC	Speech Language Concerns
SLT	Speech Language Therapy
SLTs	Speech Language Therapists
SMS	Student Management System
SRT	Student Record Transfer
STROBE	Strengthening the Reporting of Observational studies in Epidemiology
T1DM	Type 1 Diabetes Mellitus
UK	United Kingdom
USA	United States of America
UTI	Urinary Tract Infection
ABS	A Better Start
ACC	Accident Compensation Corporation
ADHD	Attention Deficit Hyperactivity Disorder
B4SC	Before School Checks
CAF	Child, Adolescent and Family Community Services
CBPA	Computer-Based Phonological Awareness Assessment
CDHB	Canterbury District Health Board

CELF-P2	Clinical Evaluation of Language Fundamentals – Preschool 2
CI	Confidence Interval
CMR	Component model of reading
COREQ	Consolidated criteria for reporting qualitative research
COVID-19	2019 novel coronavirus disease
DHB	District Health Board
DSHISS	Digital Student Health Information Sharing System
ECE	Early Childhood Education
ERHEC	The Educational Research Human Ethics Committee of the University of Canterbury
ERMS	Electronic request management system
FET	Fishers Exact Test
FSCS	Full-Service Community School
GP	General Practitioner (Family Physician/Doctor)
HIPAA	Health Insurance Portability and Accountability Act of 1996
HIPC	Health Information Privacy Code of 1994
IDI	Integrated Data Infrastructure
InterRAI-HC	Home Care International Residential Assessment Instrument
IRD	Inland Revenue Department
IT	Information Technology
ITS	Information Technology Systems
NHI	National Health Identifier
NZ	New Zealand
NZDFF	New Zealand Data Futures Forum
OM	Otitis media
PA	Phonetic Awareness
PC	Office of the Privacy Commissioner
PIRLS	The Progress in International Reading Literacy Study

SDoH	Social Determinants of Health Model
SDQ	Strengths Difficulties Questionnaire
SEMH	Social, Emotional, and Mental Health
SES	Socioeconomic Status
SIA	Social Investment Agency
SLC	Speech Language Concerns
SLT	Speech Language Therapy
SLTs	Speech Language Therapists
SMS	Student Management System
SRT	Student Record Transfer
STROBE	Strengthening the Reporting of Observational studies in Epidemiology
T1DM	Type 1 Diabetes Mellitus
UK	United Kingdom
USA	United States of America
UTI	Urinary Tract Infection

Glossary of Māori and Pasifika key terms

For the benefit of international readers, Māori language (te reo Māori) is an official language of New Zealand, originating from New Zealand's indigenous peoples, Māori. Māori terms are commonly used within the English language to describe Māori concepts and to name organisations or programmes. Pasifika terms are also important to include in this glossary as Pacifika are vital part of New Zealand growing multi-cultural society. This glossary provides an explanation of key Māori and Pasifika terms used in this thesis.

Aiga	Samoan language term for family
Ākonga	Student, pupil, learner
Aotearoa	Māori name for New Zealand
E Tipu E Rea	Grow and branch forth, the project title for A Better Start: E Tipu e Rea National Science Challenge.
Harikoa	Positive identities; joy, happiness
Hauora	Health and wellbeing
Hinengaro	Reading practices; mind, thought, intellect
Hononga	Reading together at home; connection, relationship, bond
Iwi	Tribe, extended kinship, nation, people, race.
Kāhui Ako	Community of learning
Kai	Food, meal
Kaiako	Teacher, instructor
Kaimahi	Worker, employee, clerk, staff
Kaitiakitanga	Guardianship, stewardship
Kaupapa Māori	Māori approach, Māori topic, Māori customary practice, Māori institution, Māori agenda, Māori principles, Māori ideology - a philosophical doctrine, incorporating the knowledge, skills, attitudes and values of Māori society
Koha	Gift, present, offering, donation, contribution - especially one maintaining social relationships and has connotations of reciprocity.
Kōrero	Discussion, conversation
Kura	School
Mana	Prestige, authority, control, power, influence, status, spiritual power, charisma - *mana* is a supernatural force in a person, place or object.

Mana Ake	Stronger for tomorrow, name of Canterbury District Health Board initiative that focuses on improving the health of children in schools
Mana tangata	Autonomous individual
Manaakitanga	Hospitality, kindness, generosity, support - the process of showing respect, generosity and care for others
Māori	Indigenous peoples of Aotearoa New Zealand
Mātauranga	Knowledge, wisdom, understanding
Oranga Tamariki	Ministry for Children
Pasifika	Refers to the people living in New Zealand who identify with the cultures, customs and languages of Polynesia, Micronesia and Melanesia. Pasifika are not one homogenous group, rather people whose ethic heritage is linked to countries such as Samoa, Tonga, Cook Islands, Fiji, Tuvalu, and Niue. The decision to use this term was made to follow the conventions of the New Zealand Ministry of Education
Pākehā	English, European
Rangatiratanga	Chieftainship, authority, autonomy
Taha hinengaro	Mental, cognitive and emotional health and well-being
Taha tinana	Physical health and well-being
Taha wairua	Spiritual health and well-being
Taha whānau	Social connectedness, family health and well-being
Tamaiti	Child
Tamariki	Children
Taonga	Treasure, anything prized - applied to anything considered to be of value including socially or culturally valuable objects, resources, phenomenon, ideas and techniques.
Tapu	Sacred, prohibited, restricted, set apart, forbidden, under *atua* protection
Te Ao Māori	The Māori worldveiw
Te reo Māori	Māori language
Te Tiriti o Waitangi	The Treaty of Waitangi, the founding document of New Zealand.
Te whare tapa whā	Māori health model
Tikanga Māori	Knowledge of Māori protocol and processes.
Tuakana-teina	The relationship between older (tuakana) person and a younger (teina) person
Whānau	Extended family, family group
Whānau ora	Family well-being
Wharenui	Meeting house

Chapter One The Intersection of Health and Education

It is the beginning of a new school year and Morgan, a new entrant teacher, has a class of twenty children ages five to six years from diverse backgrounds. Halfway into term two, Morgan notices one particular child, Riley, whose behaviour has deteriorated as has their academic progress. In the time Riley has been at school, Morgan has tried multiple techniques to support Riley's learning and behaviour. None of these had been useful. Morgan called Riley's parents to discuss these concerns. It was only after this teacher-initiated phone call, almost halfway into the school year, that Morgan was informed of Riley's recently diagnosed autism. With this new information, Morgan was able to put effective, targeted interventions in place for Riley's learning and behaviour. Riley began thriving at school, and as their enjoyment increased and learning improved, so did their behaviour. Morgan began wondering whether there was a way to have this information shared directly, i.e. as soon as Riley was diagnosed. As a result of the lack of information sharing, Riley effectively missed a terms worth of learning and their enjoyment of school was severely hindered, all because Morgan was not able to provide appropriate teaching and behaviour management that considered Riley's health.[1]

Teachers from schools all over New Zealand have experienced situations like Morgan's. Many of New Zealand's children are falling behind their peers academically, struggling to thrive in the current school environment, and having their school success impacted by health barriers. The increase in technology and technological advances, particularly over the last

[1] Story recounted by a primary school teacher to the researcher. Names have been changed for privacy purposes.

two decades could significantly minimise delay in teacher awareness of student health concerns and enable more effective and timely classroom adjustments and support.

This chapter will consider some of the challenges facing New Zealand's education sector, the potential for technology in facilitating solutions to these challenges and discuss the role health plays to exacerbating challenges to learning. It will finish by summarising the objectives of this research.

1.1. Learning in New Zealand: challenges faced by New Zealand's education sector

Education is a driver for success and a predictor for important life outcomes. Poor academic achievement can impact various aspects of life, including individual self-esteem, mental well-being, health outcomes (World Health Organization, 2008) and attainment of wealth (Case et al., 2005). Poor academic attainment can have a generational impact on school success. Factors such as lower maternal education, lack of positive attitudes towards school and low SES can be linked with lower family education and can contribute to generational poor school success (Banerjee, 2016).

Early education success is linked with the enjoyment of school and positive self-concept as a learner (Peixoto, 2010). Literacy skills, such as phonological awareness (PA), for children in their first few years of formal school instruction, are vital skills needed for future school success (McLeod et al., 2019). Development of PA is particularly essential as it is a key predictor of early literacy development (Gillon, 2017), and can be heavily impacted by child's health, especially their hearing (Lederberg et al., 2013). Interventions that directly target cognitive skills critical to early word reading such as PA, letter-sound knowledge and vocabulary skills show promising results (Carson et al., 2015; Carson et al., 2011; Gillon et

al., 2019). Although cognitive skills are an important influencing factor in children's learning, it is also essential to consider other domains, such as social, emotional, spiritual, and physical elements. These areas also influence learning and literacy development (Adelman & Taylor, 2006; Lederberg et al., 2013; Lewallen et al., 2015), and are commonly recognised components of children's well-being (Department of Education and Children's Services, 2007).

The bi-directional relationship between psychosocial outcomes (such as academic self-concept) and early reading success can be identified by the end of a child's first year of schooling (Chapman et al., 2000) with many of these psychosocial outcomes having a further impact on later literacy success (Education Counts, 2019). Despite the importance of early literacy development on school success, the current model of mostly cognitive intervention (intervention focussing on reading recovery programmes, comprehension and word recognition; Aaron et at al., 2008), is failing New Zealand's young people with 25% of New Zealand children not achieving in their literacy development, (Tunmer & Chapman, 2015). New Zealand literacy success, as measured by the Progress in International Reading Literacy Study (PIRLS), has fallen since 2001, with all but one of the other six English-speaking countries outperforming New Zealand (Tunmer et al., 2013). New Zealand now sits in 30th place out of 50 countries who participated in the PIRLS 2016, dropping from 23rd place in PIRLS 2011 (Education Counts, 2017). New Zealand's mean reading scores have also dropped significantly since 2001, emphasising the overall drop in reading success. This failing has exacerbated inequalities in educational success, particularly for Māori and Pasifika (Schluter et al., 2020). The PIRLS 2016 highlighted the vast disparities between ethnicities, with Pākehā reading score being significantly higher than Māori and Pasifika reading scores.

In 2014, New Zealand's Ministry for Business, Innovation and Employment (MBIE)[2] established 11 national science challenges with the "…*aim to tackle the biggest science-based issues and opportunities facing New Zealand*" (Ministry of Business Innovation and Employment, n.d.-b). One of the challenges, named A Better Start – E Tipu E Rea (ABS), identified was the potential to improve the life outcomes of young New Zealanders through five themes; Successful Literacy and Learning, Resilient Teens, Big Data, Healthy Weight and Vision Mātauranga[3] (Ministry of Business Innovation and Employment, n.d.-a).

The Successful Literacy and Learning theme of the ABS project identifies the concerning statistics in New Zealand's current literacy achievement. It focusses on early literacy success as a way to lift literacy and education outcomes, especially for children who are entering school with low levels of oral language. In order to think about early literacy success from varying lenses, ABS has taken a multi-disciplinary approach, with input from data scientists and researchers in education, public health, psychology and epidemiology all contributing. At the core of ABS is Vision Mātauranga (Ministry of Business Innovation and Employment, n.d.-c), which is operationalised by "…*a "braided rivers" approach to research, which weaves western science knowledge with traditional Māori epistemologies to gain the best outcomes for children*" (A Better Start - E Tipu E Rea, n.d.). The ABS Successful Literacy

[2] MBIE is a New Zealand ministry that supports business through policy, services and regulation. It incorporates other portfolios, such as research, science and innovation, and state services.

[3] Vision Mātauranga is a MBIE framework that gives guidance for incorporating Māori in research. The framework is developed alongside researchers, funders and the Māori community. It acknowledges the importance of Māori knowledge, resources and people (Ministry for Business Innovation and Employment, n.d.-c).

and Learning theme have identified factors related to New Zealand's literacy concerns and developed successful literacy interventions (Gillon et al., 2019; Schluter et al., 2020; Schluter et al., 2018). It is vital that literacy success remains a priority for New Zealand and continues to examine and introduce innovative, evidence-based and culturally aware interventions for New Zealand's children and their overall academic outcomes.

1.2. Education facilitated by information sharing

Improving educational outcomes for students will take a multi-pronged approach, which may include utilising rapidly developing technologies to mitigate or modify barriers to learning. There is an ongoing and exponential development of digital technologies that can be used in the health and education sectors to facilitate positive outcomes to patients and students. Integration of information technology systems (ITS) transpires across sectors, with medical technology alone worth US$405 billion in 2017 (Mikulic, 2018). The rapidly changing notion of ITS development and subsequent integration highlights the possibility for extensive ITS facilitation within sectors, especially in ones that are historically and chronically under-resourced.

The integration of electronic devices and ITS is not novel in New Zealand's education sector. There has been a growing expectation for children to be competent with computers, supported by the Ministry of Education promoting "BYOD – bring your own device" to schools (Ministry of Education, 2014). The recent global pandemic in 2020, Coronavirus disease (COVID-19), has seen New Zealand schools purchase electronic devices, so children can continue their schooling while in lockdown (Collins, 2020). Information sharing within sectors in New Zealand is also not uncommon, with several systems already sharing information within education and other government sectors. Evolution of ITS and cross-

sector information sharing is inevitable, especially when considering the current climate of technology in New Zealand. An essential part of this evolution is for any technological or information sharing advances occur carefully, in a way that minimises risks, allowing the system to reach its full potential.

1.3. Intersection and Integration of health information for learning

The intersection of health and learning, fostered by the bi-directional causal relationship between health and education, calls for greater integration of health understanding in schools. Population health models have recognised the importance of improving education as a factor of health outcomes (see the social determinants of health model (SDoH); World Health Organization, 2008). In contrast, the focus on improving educational achievement, particularly literacy achievement, has focused on cognitive intervention rather than considering health factors and other social determinants (Aaron et al., 2008). This section will consider the impact of health on learning and discuss the potential for greater integration of health information in schools to improve educational success.

1.3.1. *Impacts of health on learning*

Children with special needs or disability often struggle to achieve in the school environment, underscoring the inextricable link between health and education (O'Connor et al., 2015). However, less is known, and researched, about how subclinical and clinical illness and chronic health conditions impact education (de Bildt et al., 2005; Needham et al., 2004). If a child is often unwell, from a chronic condition, recurring acute condition, or multiple illnesses throughout the school year, that child's academic achievement, engagement and

enjoyment of school is likely to be impacted (Case et al., 2005; Joe et al., 2009; Needham et al., 2004).

Children with chronic or recurring illness often fall through the gap between regular and special education (Thies, 1999). In most cases, they do not meet the threshold for extra funding or special programmes to support their learning needs, as would a student with special needs. However, they often require specialist and school support, which are unnecessary for students with no health problems. Despite this, schools have the potential to play a significant role in a child's health, both in terms of providing intervention through health promotion, and also in terms of recognising the role health plays in a student's academic achievement (Dryfoos & Maguire, 2019). Schools have the potential to become community hubs or, as Dryfoos et al. (2005) describes, community schools. This community focus sees schools providing a range of social, health and medical services to facilitate community need and focus on improving holistic understanding and care of its' students. Community schools or hubs is not currently the standard model of schools across New Zealand, however it is gaining traction (Ministry of Health, 2009a)

Historically early learning intervention has focussed on the cognitive components, overlooking the impact of other factors, such as health, as barriers to learning and academic attainment. The component model of reading (CMR) developed by Aaron et al. (2008) acknowledges the ecological and psychological components that impact literacy achievement along with the cognitive domain. The CMR model has similarities to the SDoH (World Health Organization, 2008) in that it recognises factors outside of education that impact education. Incorporating both cognitive and non-cognitive factors into intervention strategies for learning, essentially providing a multi-facet holistic approach to children's learning, may

enable that child to flourish in their academic success (Aaron et al., 2008; Dryfoos & Maguire, 2019).

Early intervention and support for students could have significant impacts on educational attainment. Case et al. (2005) found that educational attainment and socioeconomic status (SES) in adulthood can be significantly impacted by poor health in early childhood, especially for children suffering from chronic conditions (Case & Paxson, 2006). Health and chronic conditions at age 7 and 16 years are significant predictors of earnings. While Case et al. (2005) did not find significant associations between physical impairments and educational attainment, they did find a significant correlation between mental and emotional conditions associated with lower General Certificate of Education: Ordinary Level (O-Levels) passed at 16-years. The long-term impacts of poor health from early childhood had significant negative impacts on adult life functioning and achievement. This finding suggests that "…*more attention be paid to health as a potential mechanism through which intergenerational transmission of economic status takes place*" (Case et al., 2005, p. 4). Case et al. (2005) findings support the idea of early intervention for children impacted by poor mental health. The approach of this early intervention can occur in both the health sector (where poor health can be addressed) and in the education sector (where poor health can be managed and supported in the classroom).

1.3.2. *Current health of New Zealand's students*

The extent to which children are arriving at school with health concerns that impact their ability to learn is currently unknown. There is scarce research on the prevalence of poor health in students attending school in New Zealand. The majority of New Zealand's health statistics are formulated through Ministry of Health data collection (Ministry of Health, 2009b). However, this data may be limited in acknowledging the prevalence of poor health

within the school and classroom environment. This limitation is emphasised when considering barriers to health care (for example, financial and cultural barriers) and concerns such as behavioural concerns that may not necessarily result in a diagnosis or input from health professionals.

Without an understanding of the extent of poor health in the classroom, there is limited ability to appreciate whether New Zealand students are facing unacknowledged health barriers to learning that requires changes in how the education sector delivers teaching practice and views the roles of teachers and schools. It is vital then, to establish the current health barriers to learning faced by students to ensure that there is a critical need to investigate development of current or other intervention strategies. If there are significant health barriers to learning prevalent in a classroom or school environment then is it appropriate to consider current and potential early intervention strategies.

1.3.3. *Integration of health information: potential for educational success*

Health curriculum integration in school settings has already begun, with health topics such as healthy eating, mental health and sexuality education, being part of New Zealand's health and physical education curriculum (Te Kete Ipurangi, 2014). Other schools are already incorporating other health initiatives, such as teeth brushing (Clark, 2017), onsite health services (Dryfoos & Maguire, 2019; Dryfoos et al., 2005), and sharing limited hearing and vision information (Ministry of Health, 2016b). Additional integration of health information, through parent consented health information sharing, is one way to acknowledge the impact of health in learning and allow for greater early intervention.

Adjustments to support students with chronic illness occur when teachers and education providers are privy to health information which allows them to identify at-risk students and adjust teaching practice, behaviour management and classroom environment appropriately (Cunningham & Wodrich, 2006). Thies (1999) noted, however, a teacher's access to medical records is by itself not enough to make adjustments that will effectively benefit the student. Teachers and education providers need to understand the implications a health issue has on educational achievement in order to put provisions in place to negate the impact. For instance, when teachers were provided relevant information about type 1 diabetes mellitus (T1DM) and its impacts on learning, these teachers were better able to provide appropriate, well-matched accommodations for that student (Cunningham & Wodrich, 2006). However, adequate and appropriate support from health professionals must also be available to teachers to ensure correct accommodations are made (Cunningham & Wodrich, 2012). Thus, allowing a range of health and education professionals to access crucial student health information will enable them to collaborate on how best to support health needs and champion students in the classroom setting (Thies, 1999). This approach is similar to the medical case consultations that occur in the health sector (Mudge et al., 2006). Medical case consultations are particularly utilised in the health management of complex or vulnerable clients, such as the elderly. These case consultations take a multi-disciplinary approach that pulls from resources across sectors to meet patient needs and often includes non-health supports (interRAI New Zealand, 2020). Similar consultations for children could occur in the education system, especially for children with complex needs that could benefit from wrap-around support (Thies, 1999).

By identifying the health issues within the class, and understanding the impacts that illness has on the classroom and the student, the educator can provide targeted, well-matched

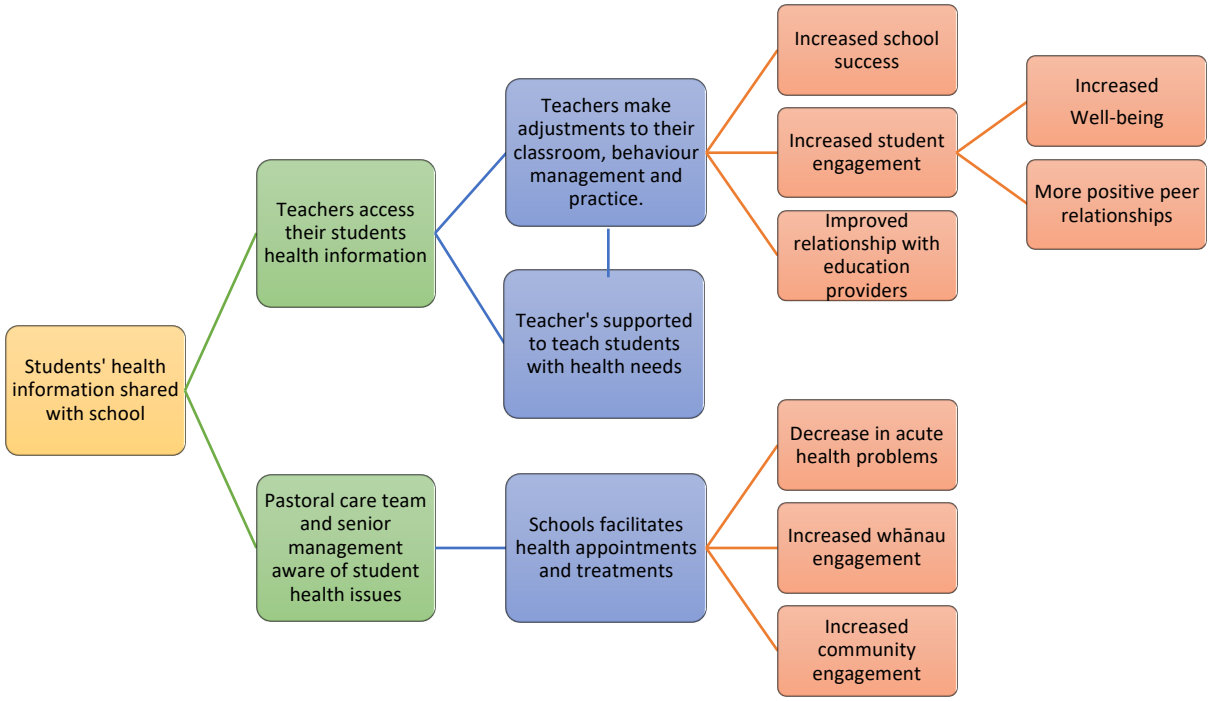
support (Wodrich, 2005). Educators can also avoid counterproductive or incorrect explanations for classroom concerns, as they are better able to understand that the concern may be attributed to health issues in the class. By adjusting the classroom environment, and teaching students with individual health needs in mind, the student will feel better able to participate and engage in the school environment, including within the classroom and more confident in their ability to achieve despite their health concerns (Dotterer & Lowe, 2011).

There is evidence that by allowing teachers appropriate, consented access to medical records and making changes based on this information, teachers believe they are better equipped to provide appropriate support and teaching for these students – they feel more confident in their ability to teach (Wodrich, 2005). It is important to note that sharing information about health concerns requires detailed information that is geared towards managing these concerns and provides comprehensive educational application in the classroom (Cunningham & Wodrich, 2006). Without this practical application, teachers may not be able to provide adjustments for optimum classroom performance. Figure 1.1 summarises the potential direct and indirect impacts of sharing health data with classroom teachers and schools.

Another way in which education providers may be able to help manage their students' health through accessing health records is being aware of student referrals and whether those referrals are followed up in the health system. Children in low socioeconomic areas are relatively less likely to receive healthcare due to a range of factors including barriers to access, unaffordability of healthcare, cultural barriers and low health literacy (Lazar & Davenport, 2018). As a consequence, they often miss secondary and tertiary health appointments (Khanassov et al., 2016; Lazar & Davenport, 2018). If school staff are aware of

Figure 1.1

Potential impacts of sharing student health information with schools



their student's health concerns, they may be able to assist in identifying and overcoming these barriers, as well as help manage their student's health. Though not a traditional role for a teacher or a school, this management might encapsulate allowing health professionals to work out of the school setting, facilitating relationships with the health sector, providing practical support (such as transport), or collaborating with health professionals to improve student well-being.

1.3.4. *Integration of health information for learning: Specific to New Zealand*

Current intervention efforts for low literacy development in New Zealand have predominantly focused on developing children's cognitive skills through programmes such as reading recovery or specialist intervention support (Te Kete Ipurangi, 2010). Many of these programmes are restorative, rather than preventative, where a child has to meet specific criteria that highlight a gap in their learning success. The impact of a restorative intervention

is that children may miss out of a significant amount of teaching before they meet the criteria for intervention. On a population-level, the effectiveness of current restorative and cognitive-based interventions in New Zealand is debated. Tunmer et al. (2015) stated "*no progress has been made in reducing the literacy achievement gap in New Zealand because the constructivist, multiple cues model of reading adopted by the Ministry of Education is fundamentally flawed*" (pg. 121). This comment highlights the need for evidence-based approaches to cognitive skill development that takes an early intervention strategy.

New Zealand schools have acknowledged the importance of the student-centric approach. They have begun integrating health care in their everyday practice, alongside existing health integration through the New Zealand curriculum (Teaching Council New Zealand, 2017). With the permission of parents, many students, particularly in primary and early childhood education, are assisted in the administration of medication at school (Ministry of Education, 2015a). This support helps ensure medication is taken as prescribed. Schools may be able to help purchase and pick up prescriptions from pharmacies for their students. Further, identifying an ill child and providing school nurses and community doctors who can prescribe the necessary medication for unwell students also breaks down barriers to health.

One New Zealand school already provides many of these services and are seen as a community hub for the area. To achieve this, the school has developed relationships with health and social services in the area, including the Canterbury District Health Board (CDHB), Children and Family Services, their local family doctors (GPs), Aviva (Woman's Refuge) and Oranga Tamariki (Ministry for Children). This school has employed multiple social workers, public health nurses, school nurses and other staff working as part of their pastoral care team. Beyond these services, the school has provided assistance to students'

whānau through transport and support with mental health appointments and picking up and administering prescriptions for students. This support and integration of social and health services into the education sphere has, according to the school, lead to a significant increase in whānau engagement and an improvement in student behaviour at school. It is just one of the many applications of sharing student health information with schools and demonstrates a possibility for education settings to be more holistic and community-centric.

As the complex relationship between health and learning is becoming more understood and accepted, schools are increasingly expected to provide more holistic, wrap-around support (Bolstad et al., 2012). This expectation is intensified by the time students spend in school, and thus there is a significant potential for education providers to assist or intervene in health (Joe et al., 2009). The holistic ethos to learning and integration of psychosocial support is supported by Gish et al. (2016). Gish et al. (2016) examined the evidence around the importance of out-of-school factors that negatively impact children's academic success. They concluded that providing wrap-around services that targeted both academic and non-academic barriers was a cost-effective strategy for supporting in school success through collective impact, cost-sharing and the integration of support services. The cost of not effectively integrating supports are not only low academic success but long-term effects such as persistent achievement gaps and greater inequality.

The ethos of holistic approaches to education mirrors Durie's (1998) te whare tapa whā model. Te whare tapa whā is a Māori health model used to understand the four cornerstones of Māori health (Rochford, 2004). The model utilises the analogy of a wharenui (Māori meeting house) where each of the sides of the wharenui reflects an aspect of individual well-being; *taha tinana* (physical well-being), *taha wairua* (spiritual well-being), *taha whānau*

(social and family well-being) and *taha hinengaro* (mental well-being). Each side works with each other, keeping the roof balanced, with the wharenui represented the interdependent nature between the sides. When one of the sides is neglected, the roof becomes unbalanced, and the child experiences poor health. This model takes a lateral approach to health, considering more than the physical child, but the context in which they live their day-to-day. The model can also be applied in an education context, where a child can flourish in a learning environment when all of their being is supported; their physical health, their mental health, their spiritual self and their social self. If schools are enabled to put in place further supports due to increased health information sharing, they may be placed to provide meaningful, holistic support with minimal delay.

1.3.5. *Using technology to facilitate health integration*

There is an opportunity for technology to facilitate the integration of health into schools by improving the mechanism in which health information is shared. The development of a digital system that shares health information within the health sector has already been effective across New Zealand, with the CDHB leading the way (with a system called HealthOne) as a response to complications sharing vital health information due to the Christchurch earthquakes in 2011 (Ardagh et al., 2012). A health information sharing system, specifically for information sharing with educators could be created alongside other similar initiatives to bridge the gap between New Zealand's health and education sectors[4] (the following chapter will discuss these initiatives in more detail).

[4] This idea was championed by Stella Ward, ex-Digital Officer (Senior Management Team) at the CDHB.

1.3.6. *Considering potential challenges*

While there is potential for positive change through the integration of health support in schools, there are still significant barriers and risks in such a change. Change and flexibility, especially on a cross-sector scale, is difficult. Health and education have been developed in different, almost conflicting frameworks. Biomedical models of health care and medical services are often focused on a deficit approach (Morgan & Ziglio, 2007), whereby health professionals identify and measure health concern(s) and fix or manage those concern(s). Health has developed significantly in the past half-century, moving into biopsychosocial models of healthcare, and considering factors outside physical health as essential considerations for illness (World Health Organization, 2008). In New Zealand specifically, many health practices have integrated Māori models of health, such as te whare tapa whā (discussed earlier in this chapter). The education sector often takes a more strengths-based, empowering approach, where teachers utilise skills and values students have, to improve academic attainment (Bolstad et al., 2012; Galloway et al., 2016). While the health sector is making changes in how it works with patients, moving toward a more holistic framework, there is still a way to go until the holistic vision of healthcare in New Zealand matches the holistic nature of New Zealand's education sector.

There are also considerable funding limitations in both New Zealand's health and education sectors. New Zealand's current constrained funding model in education limits the level of support available to meet the increasing needs of students and their whānau and presented a significant challenge for teachers and schools. In 2019, teachers around New Zealand actively participated in nation-wide strikes for increased resourcing of the education sector, including increased renumeration, greater in-classroom specialist support and increased funding for school resources (NZEI Te Riu Roa, 2019). These strikes made history with

50,000 teachers in both primary and secondary education sectors, bringing together several education-based unions such as the Post Primary Teachers Association and primary teachers New Zealand Educational Institute (Roy, 2019). The significance of this mega-strike identified the concerns the sector has in the level of teacher burnout added to lack of necessary resourcing in New Zealand schools across the country at all ages (New Zealand Educational Institute, 2019). The integration of health information sharing may add to teachers' responsibilities. A move to increased integration of health without appropriate and adequate resourcing could further add to this burden and negatively impact the availability of teachers in New Zealand.

Sharing any information also carries risks of intentional and unintentional misuse, privacy and confidentiality breaches. As long as digital information is being shared, misuse, privacy and confidentiality breaches are always possible (Ronchi & Bernat, 2016). Considerable amounts of work, by academic, private and government organisations, have focussed on how to minimise these risks (Adams & Lee-Jones, 2017; Dawes, 1996; Gil-Garcia et al., 2009). The continuing development of novel digital data systems across sectors and agencies has made this work even more critical.

1.3.7. *Understanding key stakeholder concerns – the voices of teachers and parents*

There are significant risks and barriers to information sharing (van Panhuis et al., 2014), especially coupled with digital information sharing systems. These risks and barriers can influence individuals' perceptions of sharing health information. It is essential to understand the appetite for sharing health information, especially of those key stakeholders that will be primarily impacted by or interested in the introduction of greater health information access in schools. These key stakeholders cover a multitude of individuals and organisations, such as

GPs, public health nurses, allied health professionals, researchers, young people, legislative bodies, Office of the Privacy Commissioner (PC), Ministry of Education, Ministry of Health and district health boards[5] (DHBs), among others. It is also vital to include educators and parents who will be primarily impacted through consent and operation of student health information sharing with educators. If teachers are open to accessing health information sharing and can see value being aware of such information, then this gives further justification to examine the merits of such sharing. Teachers bring a specific perspective as to how health information sharing could be helpful, or the potential barriers, risks and concerns they can foresee from this perspective. Similarly, it is essential to understand if parents are open to the idea of their child's health information being shared with teachers and can see value in it as parental consent will be required. Without buy-in from teachers and parents, sharing student health information may not be implemented efficiently, resulting in teachers not being open to accessing student health information or parents not consenting for it to be shared in the first place.

There is currently limited literature available that helps understand the public perception toward data sharing for individual purposes (Davidson et al., 2015; Howe et al., 2018; Whiddett et al., 2006) and even less that discuss teacher or parent perceptions specifically. Understanding the perceptions of teachers and parents includes a practical slant on the value, risks and suggested implementation of student health information sharing with educators. This slant may be fundamental to the implementation of a digital student health information

[5] New Zealand's health system is made up of 20 DHB's, each with separate public funds from the Ministry of Health (Ministry of Health, 2020). These funds are calculated based on the district's population numbers, age, ethnicity distribution and socioeconomic status. They are responsible for providing health and disability services that best meet the district's need.

system (DSHISS) to ensure parents who consent to access and teachers who utilise the shared information can see the value of the system, understand how the risks are mitigated and have an opportunity to voice their concerns and expectations.

1.4. Thesis objectives

This research aims to establish a health profile of children entering school with low oral language ability. This health profile will give an understanding of what health concerns children who are already vulnerable to low school success may be bringing into the classroom with them. It then takes multi-phased mixed methods approach to explore teacher and parent opinions regarding cross-sector health information sharing. It will examine the potential for sharing health information of children in their first few years of formal schooling with educators. It will consider the challenges health information sharing has to overcome, discuss the current legislation and innovation in health information sharing, as well as the potential benefits that such sharing could happen. The perceptions and opinions of key stakeholders (teachers and parents) will give a deeper understanding of how the system might be received. In order to achieve this aim, multiple objectives have been set for each phase of the research. These objectives are:

- Describe the health profile of children identified as having low levels of oral language ability in their first year at school and investigate the need for greater health-based intervention in schools.
- Identify themes raised separately by teachers and parents around sharing student health information.
- Investigate and describe any similarities and differences between the perceived challenges and benefits of sharing health information between parents and teachers.

- To take a solution-focused approach to challenges or concerns put forward by teachers and parents.

1.5. Thesis structure

Beyond this introduction, this thesis includes eight chapters. Chapter two examines the literature relevant to sharing information in the current socio-political climate and focuses on the sharing of health information. Chapter three discusses the methodological underpinnings used in the research. It includes a rationale for the multiple phased, mixed methods employed for each study and provides details of the cultural, community and ethical implications considered. The chapter also lays out the design of the thesis and provides details on how the multiple phases fit together to create a cohesive body of research.

Chapters four to six encompass the three phases of this research and discuss the findings of each phase. Chapter four establishes a health and language profile of children identified with low levels of oral language ability and asks parents of these children their views on health information sharing (phase 1). Chapter five presents phase 2, which asks teachers about their perceptions of sharing student health information. It uses findings from the previous phase in its study design, particularly in the development of the questionnaire and semi-structured focus groups. Chapter six presents phase 3, which mirrors chapter five in design, however, focuses on parents rather than teachers.

Chapter seven discusses the findings of phase 1-3 and considers the similarities and differences in perceptions of sharing health information between teachers and parents. It considers what a student health information sharing system might look like based on the perceptions of parents and teachers. This chapter also highlights the need for legislative

change based on the literature review and research findings. The final chapter discusses the implications of this research. It makes inferences to how these findings might benefit policymakers in an attempt to improve education and health outcomes for New Zealand's children.

1.6. Summary

Despite research on the negative impact some health conditions can have on academic achievement, research that establishes the extent of poor health within New Zealand classrooms is scarce. Understanding the prevalence of health issues in New Zealand's primary-aged children may help establish the effectiveness of current health management. It may also provide a more detailed context to learning barriers in which intervention strategies for literacy and school success need to consider. The research on sharing health information with schools as a potential way to help overcome these health barriers to learning is also limited. In order for student health information to be shared, research needs to discuss their needs to be dialogue from key stakeholders for both development and acceptance of such a system. This research will create a health profile of children who entered school with low oral language skills and discuss the possibility of health barriers to learning for these children. It will then examine the perceptions of key stakeholders, teachers and parents, regarding the novel idea of cross-sector health information sharing. The research will make inferences from these perceptions on the acceptance and need for a student health information sharing system.

Chapter Two Information Sharing in a Nutshell

Today's world is increasingly digitized with a vast amount of data produced daily. In 2018, it was estimated that 2.5 quintillion bytes of data were created each day, and this is rapidly accelerating (Marr, 2018). Some 90% of the world's data were generated in the last two years alone. Data are being routinely and more frequently collected from increasingly varied sources and archived, including in health and education. Data-sharing within and between various private and public organisations has become common practice, especially with the rapid development and increasing reliance on ITS and specialists (Csorny, 2013). For example, the Integrated Data Infrastructure (IDI) is an extensive national research database holding microdata about all New Zealand people and households (Statistics New Zealand, 2015). It links detailed data from health, education, justice, income and work, population and many other sources over time. Such databases can provide a holistic, detailed baseline account and history of individuals. Because these data are prospectively collected and provide complete population coverage, they may provide robust and less biased epidemiological estimates of factors and exposures of interest. Increasingly databases are utilised for personalised rather than population-based prediction and interventions and real-time use rather than retrospective purposes. In New Zealand, the B4 School Checks (B4SC) for children aged four years old are an example of health information that is collected for both predication and early health intervention. The power of such data is that not only does it allow for real-time personalised referrals and support, it also helps understand health trends and navigate future population-based intervention.

The transition to digital data makes the information susceptible to specific digital risk. It allows increased access to potentially sensitive information that can be misused if there are

no established protocols or principles (Abouelmehdi et al., 2018). The stakes of information sharing are higher as data is digitalised, more accessible and harder to monitor. Thus, the risks of data storage and sharing are potentially more prevalent and require established principles and consequences if breaches occur. The idea of sharing information, mainly information that may be considered sensitive, has the potential to elicit polarising and passionate views by the general public (Davidson et al., 2015). Despite the ongoing development of data sharing technology, research on public attitudes and perceptions of information sharing have been limited.

This chapter will discuss the pros and cons of sharing information, consider the current legislative work (and pitfalls), examine the ways sensitive information is shared with international and New Zealand examples and look into the limited research on public perception of information sharing.

2.1. The value of data sharing

There are multiple benefits to data sharing that cover many different disciplines. The benefits of data sharing in research include the reinforcement of open scientific enquiry that can be verified or refuted with the original results (van Panhuis et al., 2014). Another benefit incorporates the promotion of new research based on existing data which allows for data to be used more efficiently resulting in reduced responder burden, particularly in marginalised areas, and preventing the same data being collected multiple times (Fienberg et al., 1985).

There are excellent benefits for data sharing within and between government organisations. Research conducted by the Inland Revenue Department (IRD) in New Zealand found by sharing information, the efficiency of the organisation, detection of fraudulent and other

unlawful action and access to entitlements by customers are all significantly improved. The IRD found that staff who use the information were better equipped to provide their services, data are only required to be collected once, and the IRD was able to provide a faster service, particularly when urgent assistance is needed (National Research and Evaluation Unit, 2013).

The value of sharing health data, especially within health, has been well documented and has led to the development of several data-sharing systems. In some countries, the ability to access health data from an individual's primary care physician has enabled a fuller and faster delivery of health care in emergencies (Chaudhry et al., 2006; Ozair et al., 2015). Estonia's nationwide digital ecosystem (e-Estonia) has seen the delivery of healthcare become more efficient and accurate, whilst upholding public trust (Metsallik et al., 2018). Over 1.3 million people have their health record available to the more than 10,000 health professionals who have signed up with the system saving patients and health professionals valuable time and resources (E-Estonia, 2016). This digital ecosystem, which extends beyond health, is a prime example of how successful digital integration of government services, such as healthcare, can be achieved. By sharing health information, agencies have been able to implement initiatives that focus on public health promotion, as well as, follow health trends, and implement interventions in the face of health emergencies (van Panhuis et al., 2014). The totalled result of these three benefits has saved people's lives while respecting patient privacy and the integrity of the data.

Data sharing in schools is particularly important in the transition period. One significant benefit in the education system is the ability to transfer records, both physically and digitally between schools (Andrews & Bishop, 2012). Research by Andrews and Bishop (2012) found that sharing a student's academic progress between the student's teachers enabled the new

teacher to be actively aware of the students' learning needs. By having this knowledge, the teacher can continue with appropriate teaching practice and build on the student's prior learning while filling in gaps where the student struggles (Thies, 1999).

The social determinants of health model highlight the impact of factors outside of health that can impact an individual's health (World Health Organization, 2008). This model ascertains the effect of education on health status, identifying a positive relationship between education status and health status. This relationship looks more to be bi-directional, where both health and education status is impacted by each other (Cutler & Lleras-Muney, 2012; Zimmerman et al., 2016). Despite the relationships between health and education, the sectors remain distinctly separate and yet, both sectors often require information from the other to do their job. Health professionals often rely on teacher-report to measure symptoms of behavioural based concerns, such as in the diagnostic criteria for attention deficient disorder (Conners et al., 1998; Darling et al., 2019), while, teachers often need support from health professionals to adequately manage health in the classroom and provide a safe school environment. Sharing a student's health information has meant doctors and psychologists can make informed diagnoses, provide correct and relevant treatment plans. At the same time, schools and teachers can provide a safe, supportive environment which enables students to learn despite health concerns.

2.2. The risks of data sharing

Sharing personal data of any kind has a significant amount of risk or cost associated with it Perera et al. (2011) identified one of the risks showing the potential for a confidentiality breach where unauthorised individuals became aware of confidential information. Davidson et al. (2015) identified perceived risks of sharing information. These risks included the

misuse of the information, particularly for direct commercial or personal gain, taking advantage of vulnerable groups, profiling, stereotyping or disadvantaging certain groups of people, and use in surveillance.

Along with the above, data sharing in the health sector has its more specific and potentially harmful risks. One of these is the harm which could result in patients not fully disclosing symptoms or illness to their physicians. A patient may feel uncomfortable with other people knowing about her medical history, as it may be detrimental to how the individual is viewed by others (Statistics New Zealand, 2017b). As a result of non-disclosure, patients may be misdiagnosed or undiagnosed, which may result in a more severe condition requiring greater intervention and treatment than it would have otherwise (Adjerid & Padman, 2011; Statistics New Zealand, 2017b).

When sharing student health information with teachers, misuse of information, such as incorrect matching and labelling, are risks that could lead to harmful consequences. Incorrect matching is a situation where a medical condition is matched with the wrong student (Godlove & Ball, 2015). The consequences of this include a student not being identified as needing extra support by the teacher due to a medical condition, and teachers making ineffective classroom arrangements due to incorrect matching. Labelling, on the other hand, is where students and whānau are labelled negatively based on a student's health records. This labelling (i.e. a student with attention deficit hyperactivity disorder (ADHD) labelled as hard work or naughty student) is detrimental to the student's achievement, well-being and self-esteem (Henderson & Thornicroft, 2009). Another potential risk is the potential for inaction or actions that do not fit with parent expectations. This could occur when parents believe that because student health information has been shared teachers will respond to that

information a certain way, but, due to workloads or understandings, action is either not taken or is different from the parent's expectations. While it is not a novel notion, the idea that knowledge is power is more accurate than ever, thanks to the growing reliance on technology and digital data. Davies (2016) noted the growing responsibility of governments to play a role in ensuring knowledge and data are used in a meaningful way, with stringent measures needing greater attention in research to safeguard from misuse and risks.

2.3. Research vs routine data sharing

It is essential to note the differences between data sharing for research purposes and routine purposes as the importance of specific principles will vary depending on the purpose of data sharing. Data sharing for research purposes must undergo ethics approval of which anonymity of the data is considered the best way to ensure the participant's confidentiality is met (Grinyer, 2009). Routine sharing, however, will often focus its privacy obligations and principles through ensuring the information is protected by the individuals who have it. For example, routine sharing in healthcare is common, particularly when referring patients to specialists. This data sharing is unable to be non-identifiable. Thus, the priority to maintaining data sharing principles will be through ensuring those who have access to the information (physicians and specialists) will keep that information secure physically and digitally. Emphasis on particular principles, therefore, is placed differently depending on the purpose of data sharing.

2.3.1. *Consent on data sharing*

Consent for information sharing can be given in several ways. The National Ethics Advisory Committee (2018) dedicates a full section of their report on informed consent in research and

the different ways it can be attained. The report highlights the importance of recognising the rights of mana tangata (autonomous individual) in giving permission to participate based on the informed risks and states it is the responsibility of those performing the action that requires consent, to ensure those who participate are fully informed.

While the National Ethics Advisory Committee (2018) focuses on consent within research, many of the key messages can be transferred to consent for sharing information, particularly integrated consent. Current health information sharing systems in New Zealand incorporate an opt-out consent process where patients are thought to give consent automatically when receiving health services and can withdraw their consent at any time (HealthOne, 2016c). Opt-out consent can be more pragmatic (Clark & Findlay, 2005). For this research, opt-out consent could be given automatically when the child enrols at school. This consent process has the potential to minimise the paperwork required for consent, however, if not done appropriately, parents may not fully understand the risks and not be fully informed.

Multi-disciplinary information sharing will require informed consent, with participants in the process being made fully aware of who the information is being shared with, and for what reason. In New Zealand, there have been instances where cross-sector information sharing has led to adverse outcomes for whom the data belongs, such as in the 1970s dawn raids (McFadden, 2015) and more recently with, the Ministry of Justice, Oranga Tamariki and Ministry of Social Development (Bateman, 2019). These examples will be discussed in further detail later in the chapter and thesis. It is vital that any cross-sector, multi-disciplinary information sharing is appropriately and fully informed, with clear boundaries understood by the owner of the information and those who have been permitted to use it.

2.4. Development of data sharing principles

As the ability to collect and share information and data has grown, there is a need for discussion and guidance on proper protocol and protection. As a result, documents that consider discipline-specific confidentiality and privacy have been established and have resulted in a variety of documents needing consideration before the information is shared. Health information sharing in the United Kingdom (UK) has multiple Acts and standards to consider and follow. The Data Protection Act 1998 (UK), covers data from all sectors that are shared ("Data Protection Act 1998 (UK),"). Eight principles from the Act ensure that collection is lawful, for a specific purpose and that purpose is known, the information is accurate, relevant, kept secure, kept for a limited amount of time, protects the rights of the subjects, and is not transferred to territories that do not have adequate protection of that data.

The development of the Caldicott Principles[6] has considered and incorporated some of the Data Protection Act 1998 (UK) while creating principles specifically designed for health information. It includes six principles more specific to the health sector such as principle four "access to the information should be on a strict need to know basis" (pg. 3), and principle five "everyone should be aware of his/her responsibilities to respect clients confidentiality" (pg. 3). Principle six incorporates complying with current law including relevant legislation such as the Data Protection Act 1998 (UK), the Police and Criminal Evidence Act 1984 (UK), and the Human Rights Act 1998 (Wales Centre for Pharmacy Professional Education, 2017).

[6] The Caldicott Principles set out several principles for sharing health information across the United Kingdom's National Health System (NHS). The principles ensure that patient information is protected and used only when is appropriate and necessary to do so (Wales Centre for Pharmacy Professional Education, 2017). They have most recently been revised in 2012.

In the United States of America (USA), the Health Insurance Portability and Accountability Act (HIPAA) was developed and implemented in 1996. Title II of the Act requires healthcare providers and organisations to adhere to regulations that dictate rules around privacy, confidentiality and security of health data that is shared, stored and handled (O'Herrin et al., 2004). These rules are relevant only to health data, health providers, and organisations that handle health data, such as insurance companies. An article by Lee and Gostin (2009) designed ten governing principles for the collection, storage and use of public health data. The Centre for Disease Control has used this research to create "Ten Guiding Principles for Data Collection, Storage, Sharing, and Use to Ensure Security and Confidentiality" outlined in Appendix A.1. Many of these principles can be applied to all varieties of data sharing, as they emphasis individuals right to privacy, particularly identifiable data while recognising the that sharing data has significant use for communities and research.

The need for data and information sharing in the UK has grown. In health and social care services, the need for agencies to work collaboratively with other service providers has increased due to the restrictions and limited capabilities of an individual agency (Gil-Garcia et al., 2009). Research by Richardson and Asthana (2005) looked at the policy and legal influences that impact information sharing between health and social care services. The paper discusses the shift towards collaboration between organisations able to work together for a common goal and how this collaboration is specifically essential in sectors where human health and well-being are concerned. Richardson and Asthana (2005) identify ease of information sharing as a necessary component to successful collaboration, with one of the most challenging barriers being the lack of one particular guiding document that results in the need to consider multiple Acts and other legal documents. For example, when discussing

information sharing for children's protection purposes in the UK, 31 statutory provisions have to be considered.

Further studies in the UK by Cleaver et al. (2004) concluded that a significant barrier to information sharing for some organisations in social care services and health "…*lies squarely around the legal position of sharing information…*" (p. 50). Leaders of these organisations are *"… not only … unclear about the relatively untested legal position, they are confused by the sometimes conflicting guidance issued by different government departments…"* (p. 50). his lack of a unified legal framework in regard to information sharing, with particular examples in social care services and health, is also a similar problem in New Zealand. Development of a larger precise document for information sharing in general needs to be prioritised (Adams & Lee-Jones, 2017).

2.5. New Zealand data sharing examples

Within the New Zealand context, documents outlining the principles of data sharing, like overseas, have been developed in a largely discipline-specific manner, with few considering inter-disciplinary data sharing. The Privacy Act 1993 is an overarching document that forms the foundation in the development of further privacy and information sharing codes. Due to the different needs of data privacy, sectors, and in some cases organisations, have created their own rules that incorporate the Privacy Act that is specific to the privacy needs of their data (e.g. Health Information Privacy Code, 1994; HIPC).

The New Zealand Privacy Act 1993, which has had numerous updates since its creation to keep up with the advance in data sharing capabilities, set out twelve privacy principles that set out how to handle personal information for organisations and individuals ("Privacy Act

1993,"). These principles cover the collection of personal information (principles one to four), storage and security of personal information (principle five), requests for access to and correction of personal information (principles six and seven, plus parts four and five of the Act), the accuracy of personal information (principle eight), retention of personal information (principle nine), use and disclosure of personal information (principles ten and eleven), and using unique identifiers (principle twelve). Appendix A.2 has a more in-depth summary of each principle.

Government departments regularly involved with data sharing, will often have a document that sets out principles or guidelines around data confidentiality and privacy, as well as the role of that individual organisation in information sharing. Statistics New Zealand work under the guidance of the Statistics Act 1975, which states guidelines government statisticians must follow and the rules regarding the integrity of the data that is collected, managed and shared ("Statistics Act 1975,"). It works alongside other legislation such as the Privacy Act 1993. Many legislative documents in New Zealand around data sharing are formed by the Privacy Act 1993, developed for their specific field (for example the HIPC 1994). The twelve principles of the Privacy Act 1993 ensure the use and management of health information is transparent, the data is secure and correct, accessible to the individual, used only for its intended purpose and is unidentifiable unless exceptions apply.

Principles around sharing health information are particularly well developed due to the potential benefits and sensitive nature of sharing such information. The HIPC dictates special rules for health agencies in New Zealand (Office of the Privacy Commissioner, n.d.-a). It acts as a set of principles for identifiable health information that is collected, used, stored and disclosed, and covers various health organisations from primary health organisations to rest

homes. The HIPC consists of 12 rules (see Appendix A.3 for all 12 rules) and covers the purpose of collection, privacy (especially for identifiable data), storage and management, and who can access the information. The rules are set based on the Privacy Act 1993, with only small differences to be relevant to their place in the health sector. These differences include that the HIPC involves only health information and acknowledges that the use of unique identifiers, particularly the National Health Index number (NHI)[7] is common in the health sector (Ministry of Health, 2017).

The HIPC dictates any data sharing that includes health information; thus, any sharing of health information must adhere to this code. In order to ensure professionals are following the code, each agency which is accountable to the HIPC has a nominated individual who is responsible for following up any complaints made (Office of the Privacy Commissioner, 2008). There is an expectation that if a complaint is made, that the designated individual is to look into the breach "…and facilitate the fair, simple, speedy, efficient resolution of complaints…" (Office of the Privacy Commissioner, 2008).

Work by the New Zealand Data Futures Forum (NZDFF) has identified multiple economic, social and personal opportunities in New Zealand, that that could benefit from sharing data. To fully tap into these opportunities, the NZDFF have recognised the importance of developing clear principles around sharing data. As a result, the NZDFF have created four guiding principles*; trust, value, inclusion* and *control*. These values are intrinsic to harnessing

[7] A NHI number is assigned to every individual who accesses health services in New Zealand (Ministry of Health 2017). The number is usually assigned at birth, though travellers, immigrants and citizens born overseas are assigned one when they first access New Zealand's health services. The number is also designed to incorporate the Medical Warnings System, a system that is designed to warn health professionals regarding any recorded risk factors when they are treating the patient.

the opportunities that data sharing provides individuals, organisations and governments. Appendix A.4 discusses the four principles in more detail. As future data-sharing occurs, incorporating these four principles created by the NZDFF will lead to a common framework and consistency for data sharing principles, while allowing flexibility to fit with the types of data being used.

Limited multi-disciplinary research and routine data-sharing have occurred in the New Zealand context. Organisations who have utilised this multi-disciplinary approach have had to think about the ethical and legal concerns that arise when working with multiple sectors. Statistics New Zealand has done extensive research to create policies and principles that correspond with various acts and documents to incorporate various information into its IDI system. The IDI is a system that integrates routinely collected data from multiple and separate sources for research and statistical purposes. These sources include information from government agencies, Statistics New Zealand surveys (e.g. the 2018 census) and non-governmental organisations and covers a wide range of data including household income, education, health information, social welfare, immigration, and justice (Statistics New Zealand, 2015). This information is linked together and anonymised to create an extensive IDI database. It is one of the most multi-disciplinary data integration systems in New Zealand and has many different risks, benefits and Acts to adhere to and analyse.

Statistics New Zealand is foremost governed by the Statistics Act 1975, but when considering creating a document regarding privacy concerns for the IDI there needed to be principles from other Acts (most notably the Privacy Act 1993) as well as creating their own principles. Statistics New Zealand developed four principles, 1) ensuring that the benefits of integration outweigh privacy concerns and risks associated, 2) data is only used for statistical and

research purposes, 3) integration is conducted transparently, and 4) data will not be integrated when an explicit commitment has been made to respondents that prevent such action (Statistics New Zealand, 2017a). When the types of data expanded, additional consideration to appropriate legislation was needed. The introduction of health data into the IDI meant the HIPC principles had to be incorporated. The IDI is an excellent example of a system which utilises multi-disciplinary information sources for research data sharing purposes while maintaining a high level of privacy and security that is considerate to the different data it encompasses.

Most privacy breaches in New Zealand are referred to the PC. When a breach of the Privacy Act 1993 (or PC issued "Codes of Practice") is made, an individual who is affected by the breach can make a complaint to the PC for investigation (Office of the Privacy Commissioner, n.d.-b). If there is no agreed resolution in the PC investigation, and the PC is satisfied there has been a breach, the PC "…may refer the complaint to the Director of Human Rights Proceedings (the Director) so they can bring the case to the Human Rights Review Tribunal" (Office of the Privacy Commissioner, n.d.-c). Westpac New Zealand (one of the leading financial and banking institutions in Australasia) released Nicky Hager's financial information to the New Zealand Police unlawfully, and in 2019 the parties agreed to a settlement after the breach was investigated by the PC (Office of the Privacy Commissioner, 2019a).

More recently, the Social Well-being Agency, previously named the Social Investment Agency, introduced the Data Protection and Use Policy (Social Investment Agency, 2019). It created five key principles that considered and incorporated current legislation (e.g. the Privacy Act, the Oranga Tamariki Act, and the Family Violence Act) which dictated how

information is collected, stored, managed and used. Each of these key principles incorporated Te Ao Māori values. The Social Well-being Agency (SWA) shifted the focus from rules that dictated use, to focus on working with the data in a way "…*that respects people, their information and their stories*" (Social Investment Agency, 2019, pg.1). The Data Protection and Use Policy guided how to restructure and integrate the five principles as well as providing guidelines for information sharing that were built through these principles.

The Privacy Act 1993 is to be replaced by the Privacy Act 2020, which will come into force on December 1, 2020 (Office of the Privacy Commissioner, 2020a). This replacement acknowledges the development of technology, the increased ability and use of information sharing and the potential for organisations outside of New Zealand to access, use and store information about New Zealand citizens. It will introduce a thirteenth principle (related to responsibilities of the information sharer when sharing information outside of New Zealand), introduce new privacy breach laws and confirms companies overseas who do business in New Zealand must comply with the act ("Privacy Act 2020,"). It will also update three current principles to include provisions to collecting only information for a lawful purpose, more protections for young people and the ability to refuse access to personal information on the grounds of safety. These changes will have an impact on other legislative documents, especially ones built on from the original Privacy Act 1993, such as the HIPC. For these legislative documents will need to ensure their codes reflect the changes made by the new Privacy Act 2020. The updates to the Privacy Act 2020 show the impact of increasing digital information in New Zealand. It considers the recent work of Oranga Tamariki and the SWA, which requires further protection for young people's information and the ability to share information more readily if there is a safety or well-being concern for a child (or adult).

In order for information to be shared, there is a large number of considerations to be made. Not only must information sharing align with the Privacy Act 1993 (2020) principles, but it must also consider other legislative requirements. In some cases, particularly if the reason is for safety reasons, information sharing may be easier to execute. However, for the average citizen, the number of legislative criteria for information sharing may be too daunting, or interpretations (by individuals or organisations) of legislative principles may be misconstrued leading to unnecessary barriers to information sharing.

2.6. The relationship between health and education

There is a growing body of research that examines the impact of illness and poor health on academic achievement and school success (Cutler & Lleras-Muney, 2012; Field et al., 2001; Needham et al., 2004; O'Connor et al., 2015; Palloni, 2006; Thies, 1999). As adults, we experience how the common cold can adversely influence our ability to work, how it hinders our ability to be productive, and the number of work hours lost (Bramley et al., 2002; Dicpinigaitis et al., 2015; Hellgren et al., 2010). This is a growing area of research across health and education as the awareness of holistic, child-centric model of learning increases.

Chronic illness

If a child is often unwell, from a chronic condition, recurring acute condition, or multiple illnesses throughout the school year, that child's academic achievement, engagement and enjoyment of school may be adversely impacted (Case et al., 2005; Joe et al., 2009; Needham et al., 2004). Thies (1999) examined how chronic illness impacted educational attainment and how that impact occurs both due to chronic illness and the illness itself. For example, diabetes can impact learning through impaired concentration, difficultly with visual scanning and reading. Case et al. (2005) found that having a chronic illness when aged seven years old

negatively impacted the number of O-Level exams completed and passed when the child was aged 16 years. This finding is consistent with Thies (1999), who writes:

> *"The combination of chronicity, absence, and side effects of illness and treatment are subtle, but the cumulative effect is potentially damaging. Falling behind academically leads to catching up and catching up takes time away from keeping up. Self-confidence and achievement motivation are undermined" – Thies (1999, pg. 395)*

Children's learning is similarly hampered by common illnesses, with both acute and chronic illness can significantly restrict a child's learning and development (Quach & Barnett, 2015). For example, low blood sugar levels often experienced in T1DM can lead to a decreased ability to concentrate (Wodrich, 2005). Recurring ear infections such as otitis media (OM) which impact hearing, can negatively impact literacy development (Case et al., 2005), especially in early learners (Friel-Patti & Finitzo, 1990; Kaplan et al., 1973; Roberts et al., 2002; Roberts et al., 1986; Winskel, 2006).

Vision and hearing

Vision and hearing can have significant impacts on literacy development especially in the first few years of formal school instruction (Lederberg et al., 2013; Wang et al., 2011; Yiengprugsawan et al., 2013). Recurring OM, a common ear infection in children, has been found to particularly impact literacy development (Winskel, 2006; Yiengprugsawan et al., 2013). The impact of vision and hearing will be expanded in chapter four.

Asthma, eczema and other chest and skin -related illness

Asthma and eczema are other common childhood illness that can impact educational outcomes in students. New Zealand has high rates of asthma, with 14% of children being diagnosed with asthma (Ministry of Health, 2019). Asthma is associated with higher levels of school absences (Koinis-Mitchell et al., 2014) as well as poorer academic achievement (Kim et al., 2017), and has higher prevalence and poorer day-to-day management in low socioeconomic communities (Von Bülow et al., 2015; Zahran et al., 2018). Similar to asthma, the impacts of eczema or dermatitis can hinder academic performance. Lewis-Jones (2006) described how eczema could have profound negative impacts on children's lives. It can affect several life factors and can have physical, psychological, and psychosocial effects that can have consequences in a child's concentration and ability to learn. Ongoing absences due to illness can also lead to children's learning that falls behind that of their peers. Where health concerns are poorly managed, the child may be unable to catch up and thus experience a persistent learning disadvantage.

Poor Sleep

A meta-analysis performed by Taras and Potts-Datema (2005b) highlighted the vast breadth of literature that demonstrates the varying negative impacts of poor sleep on a range of developmental factors. Poor sleep can reduce cognitive functioning such as attention, memory and intelligence (Harding et al., 2020), while it can increase problematic and distracting behaviour (Astill et al., 2012; Blunden et al., 2000; Galland et al., 2015). Early identification and management of sleep disorders before and during school instruction may lead to improving school success (Taras & Potts-Datema, 2005b).

Mental illness

Academic achievement is associated with mental health and self-esteem; a vital component for and life outcomes (Aryana, 2010; Rahmani, 2011; Rathi, 2010). Mental health issues can be even more complex than physical health concerns as individuals who have a mental illness often suffer from a lack of empathy by society and sufferers are frequently stigmatised by others and remain undetected for longer (Rusch et al., 2005). Depression and anxiety both adversely impact on academic achievement, sleep, and general well-being in adolescents (Field et al., 2001; Needham et al., 2004; Taras & Potts-Datema, 2005b; Woodward & Fergusson, 2001)

Carroll and Hurry (2018) found that incorporating school-based strategies that targeted social, emotional and mental health (SEMH) concerns improved students' motivation for learning and decreased the likelihood of exclusion. These findings indicate the bi-directional possibility between school success and maintaining positive SEMH. Price and McCallum (2016) stated, "…*this holistic focus on the child has been viewed as a way to advance academic achievement and contribute to quality of life*" (pg. 8). Sharing potentially sensitive information between organisations, however, is an essential tool for effective integration. Currently, this tool is facing multiple barriers from political, legislative and social factors.

The effects of behavioural challenges associated with some diagnoses, such as ADHD, Autism and Conduct Disorder, can impact the child's ability to concentrate and learn (DuPaul et al., 2001). In primary school settings, these behavioural illnesses can often result in removal from the teaching environment or suspension (Tate, 2013). The removal of the child from the teaching environment means the child misses vital learning and can fall further behind.

Whether a student suffers from an emotional or physical illness, that student is more likely to be left behind by the education sector. Interventions must look to minimise the impacts of physical illness and poor SEMH. These interventions must be put in place to ensure efficient and appropriate management within the health system is in place, allow teachers the ability to adjust the classroom environment and teaching practice based on the health condition in their classrooms. This intervention will allow teachers and schools the ability to provide support to the child, whānau and community through more practical intervention.

2.7. Current data sharing in New Zealand

Multi-disciplinary routine data sharing is occurring in New Zealand, most of which use the existing principles in the Privacy Act 1993. An information-sharing agreement between IRD and the Department of Internal affairs allows passport information to be disclosed to IRD to enable it to follow up defaulting student loan holders located overseas (Ministry of Internal Affairs & Inland Revenue Department, 2014). A similar agreement between the IRD and New Zealand Police allows the disclosure of information that will assist Police in investigating crimes and reduce criminal offences (New Zealand Police & Inland Revenue Department, 2015). Another agreement allows the disclosure of information between multiple relevant agencies (e.g. the Ministries of Social Development, Justice, Health and Education) to identify children at risk, assess their need and inform the appropriate service response ("Information Sharing Agreement for Improving Public Services for Vulnerable Children 2015,"). These agreements utilise the Privacy Act 1993 as a guiding document to information sharing. Due to the way these three agreements are written, all are particular to the situation and content that information is being shared (and thus cannot be re-used without further legislative work).

2.7.1. *In the health and education sectors*

Data and information sharing have a prominent, already established, place in New Zealand's health sector. Referrals are made, usually by a patient's GP, to a specialist that outlines the patient's relevant medical history, why they are being referred and other relevant information. The Electronic Referral Management System (ERMS) was launched in the Canterbury district in 2009 as an e-referral system that aims to provide a more accessible, accurate and efficient referral system (Canterbury District Health Board, 2017). It has since been rolled out throughout the South Island. The ERMS is a highly valued, highly effective referral patient management system that has decreased waiting times, provided more equitable access to care, and eased referrals between health providers(Canterbury District Health Board, 2013). The ERMS is provided by HealthPathways which limits the ability to refer to health professionals who are responsible for that referral, i.e. GPs. The system was independently reviewed by the PC to ensure it upheld the principles and legislative rules of the HIPC and Privacy Act (Deloitte, 2015; HealthInfo, 2014).

Implementation of an electronic information sharing database labelled HealthOne is currently underway in DHBs across the South Island of New Zealand (HealthOne, 2016a). HealthOne is an electronic shared care record view designed to record and store vital health information such as GP records, prescribed medication and test results. The programme is based on a role-based matrix, where the role of the health provider dictates what role relevant information is accessed. Different users include GPs, nurses, pharmacists and pharmacist technicians, as well as other health and allied health professionals. The information on HealthOne is used to provide safer and quicker health care to patients when visiting multiple medical professionals. This system is adopting the principles of the HIPC not only in its

implementation but also its development. The privacy framework that was developed for HealthOne goes through every rule of the HIPC to summarise the implementation approach and mitigate any potential breaches (HealthOne, 2016b). For example, as the number of health professionals whom the CDHB allowed access to this system increased, the more stringent protocols regarding this access was put in place with each healthcare professional needing to be verified via the health practitioner index provided by the Ministry of Health. The framework ensures checks and balances are in place by auditing each professional's use of the system and the consequences if the system was to be abused by a professional, i.e. formal warning, removal of access and advising the healthcare provider's registration authority and the PC (HealthOne, 2016b).

The New Zealand education sector is guided by the Education Act 1989. In terms of data sharing, the Education Act dictates that school records must be transferred between schools (Ministry of Education, 2015b). These records can include enrolment information, assessment records and attendance records. This form of information sharing is done electronically through the Student Record Transfer (SRT) and between other Student Management Systems (SMS). Ministry of Education (2015b) discuss the benefits of the electronic SRT which included decreased costs associated with administration, a quicker collection and response to incoming student numbers and needs, and a safe and accurate way to transfer information about a student.

Unfortunately, the SRT has not been adopted by a vast majority of education providers for several reasons. One of these reasons includes how schools in New Zealand are run – they fundamentally autonomous bodies, governed by their board of trustees and have preferred ITS (Hood, 2019). Public schools in New Zealand are funded on a student number basis,

resulting in school competing to draw students to their establishments. This competitive nature, along with issues around resourcing, may limit transitional information sharing (Burgon & Walker, 2013). SMS are also struggling to be utilised effectively due to problems with interoperability leading to education information not being shared, increased workload for schools and the Ministry of Education, and parents receiving inconsistent and potentially conflicting views on their child's success. This is mostly due to the number of different SMS products that struggle to work together. The Ministry of Education has suggested a centralised repository for vital student information so that this information is easily shared between schools regardless of the SMS product they are using (R. Barrow, Group Manager for Data and Information Stewardship at the Ministry of Education, personal communication, May 30, 2017). This suggestion is currently under consideration by the Ministry of Education and is yet to be fully operationalised.

Dalziel (2009)[8] wrote a guide for teachers, principals and board of trustee members that review the Privacy Act, 1993 in schools. The book discusses the need to consider relevant acts depending on the particular situation. Dalziel (2009) considers the required sharing of student records between schools, mentioning the "… *difficulty appears to be deciding whether or not to share other information that is not required to be shared as a matter of law*…" (p. 31). Dalziel notes that in this situation consideration should be made to "…*principle 11 and professional codes of conduct/ethics when making a decision about disclosure to a forwarding school*…" (p. 32). The book highlights the need to consider multiple documents and legislation when considering privacy within the education sector as

[8] Kathryn Dalziel is a leading privacy lawyer in New Zealand. Dalziel provides services for consultancy services and legal advice to the Office of the Privacy Commissioner and is a leading source for providing information on privacy legislation in schools and other education institutions.

well as the lack of an overarching document and procedures on how to handle sensitive information appropriately. These factors have resulted in a lack of confidence in sharing information, to an extent where it is easier to follow the status quo.

2.7.2. *Between the health and education sector*

Currently, there is limited sharing of personalised health information between schools and health providers in New Zealand. There is minimal digital health information sharing occurring between schools, even when children transition from early childhood education centres to primary, or primary to secondary, despite the positive association between sharing student information and school adjustment (Cook et al., 2017). Most of the health information sharing occurs between teachers and parents, i.e. through parents informing school staff of any health concerns their children have.

School Enrolment

When a child enrols into a new school, parents are asked to fill out an enrolment form. On this form, though not formally required, many schools ask parents about the child's health, and whether they have any concerns that would be helpful for the school to understand. These concerns can include allergies, serious or life-threatening conditions, immunisation status, and other medical conditions. Currently, this is the only formal documentation of health information sharing between parents and schools (Education Counts, 2015).

Parents are primarily responsible for disclosing their child's health conditions at that time. One of the apparent disadvantages of this approach is that it only gathers health information at one point in time (at enrolment) and may quickly become out-of-date. It does not discuss any ongoing investigations, provide ongoing health information such as new diagnoses or

update previous diagnoses, which leaves schools with potentially incomplete and incorrect health information on their students. This incomplete or incorrect information impacts a school's ability to act in a health emergency while hindering their ability to understand the student's health background and could disadvantage the student if the school acts on incorrect information (Lee, 2019).

B4 School Check (B4SC)

The health information gathered at B4SCs are currently some of the only readily available health information able to be accessed by school principals. B4SCs are conducted when a child is four years old by a public health or Plunket nurse (Ministry of Health, 2016b). It focuses on identifying any health, behavioural, developmental or social concerns before a child enters school to ensure their learning and development is adequately supported at school (Ministry of Health, 2016b). This free and intended universal check-up includes (Ministry of Health, 2008):

- hearing and vision screening, measurement of height and weight,
- questions to look at child behaviour and development using the Strengths and Difficulties Questionnaire (SDQ) and Parental Evaluation of Developmental Status questionnaire,
- an oral health screen and enrolment into a registered school dental clinic,
- if any concerns are identified in the B4SC, referrals to the appropriate service (health, education or social services) is made, along with providing health information advice and support where appropriate.

The B4SC has had broad uptake level, with 57,985 children screened in 2015/2016 (92%). However, the remaining 8% who do not participate in the B4SC are more likely to experience poor health than those who have participated (Ministry of Health, 2016b; Shackleton et al., 2018). The B4SC hearing and vision information are available for principals through the *Enrol* system (Ministry of Health, 2013). When accessing B4SC information, principals are bound by the Privacy Act 1993 and Education Act 1989, as well as principles from the HIPC.

It is important to note that only approved staff members within education that can access this information, usually the principal or assistant principal, adding further work for senior management to ensure this information disseminated to the appropriate teachers. The B4SC is the only universal government-run, digital health information sharing with schools that occurs in New Zealand currently. While it has had high levels of uptake, it has limited use in that the information that is collected is only valid for a short period as it takes a snapshot of a child's health at four-years of age. It does not keep a record of any further developments in the child's health.

2.7.3. *Alternative health to education information sharing*

Due to the limited capacity of regulated and procedural health information sharing, teachers may only be able to find out about student health concerns by making direct contact with the student's parents. This contact often requires behavioural or learning concerns be presented in the classroom, requiring the teacher to make, often out of hours, contact with parents and discuss the potential reasons for these concerns. This contact may be a simple email, a phone call or catching up with the parent either casually or in a scheduled meeting (American Federation of Teachers, 2007).

This reactive form of information sharing may lead to delayed learning for the student as the teacher first must recognise the concern, get in touch with the parents, discuss what they have concerns with, why these concerns might be happening and where to next (American Federation of Teachers, 2007). Teachers can find themselves in a precarious situation when asking questions about student health information, especially if it is early in the students schooling with that teacher and a relationship with the parent or caregiver has not been established or developed.

One innovative digital health information sharing system, iMOKO[9], sees schools and communities as vital and invested groups who can participate and effectively assist the health system. The iMOKO programme recognises the high cost of barriers to health care access and bought simple digital health systems into schools with high proportions of Māori students. The initiative began in a small primary school in Northland, New Zealand and has since expanded into over 260 early childhood, primary and secondary schools throughout New Zealand (Navilluso Medical, 2016b). iMOKO trains school staff to be able to conduct an in-depth health assessment about common childhood illnesses in schools, such as skin or throat infections (Navilluso Medical, 2016b). The health assessment is then digitally sent to a telehealth clinician that will write a treatment plan (including prescriptions), who sends it straight to parents via the iMOKO Parent App. iMOKO bought health care to children in schools and allowed community and school members to play an active role in managing the health of their children at school. The main aim of this design was to utilise digital technology and the supportive environments created by schools and communities to help

[9] iMOKO is a healthcare programme developed by Navilluso Medical that allows bi-directional health information sharing. It was developed to address health inequalities for Māori based in Northland, New Zealand, utilizing low-cost, digital technology (Navilluso Medical, 2016b).

minimise the cost and wait times of primary health care and providing "… *more health to more people for less money*" (Navilluso Medical, 2016a). While health information is shared from schools, rather than to schools, iMOKO highlights the potential good that can come about if investment into a digital health information sharing system was a priority. iMOKO acts as a model for creating a digital way to share health information with schools and teachers in the interests of supporting students to learn and thrive in the school environment.

2.7.4. *Mana Ake – Leading Lights*

One of the most progressive developments the integration of health in education is the CDHB's Mana Ake initiative (https://manaake.health.nz). Mana Ake – Stronger for Tomorrow in a Canterbury initiative that provides support for children aged 5-12 years through school. The initiative was launched in 2017 and provides several aspects of support (i.e. psychologists, social workers, counsellors, teachers and youth workers), for both teachers and whānau (Canterbury Clinical Network, 2020). These resources are provided to children who are experiencing ongoing mental well-being issues. Mana Ake – Stronger Tomorrow is built on the ethos of ensuring all children are supported in their health and well-being by utilising and assisting an array of professionals, including teachers, social workers, and psychologists.

One facet of Mana Ake is their Leading Lights website which is designed particularly for educators (https://www.leadinglights.org.nz). Leading Lights helps educators by providing guidance and ideas on how to manage and respond to different physical and mental health needs that might be impacting the child in school. It acts as a responsive resource once information has been shared, in that it provides educators guidance on symptoms, common misconceptions, outside services available in the Canterbury region and links to appropriate

documentation. Its responsive manner means it is continuously being updated, with a trauma pathway created in response to the 15th March 2019 mosque terror attacks in Christchurch (Edwards, 2019). This responsiveness has meant the tool is flexible and monitored with best practice guidance that is easily updated with new findings in research development (C. Shepherd, Project lead for Mana Ake, Personal Communication, June 12, 2019).

2.8. Attitudes towards information sharing

The literature on public attitudes toward data sharing remains scant in both the scientific and governmental areas (Whiddett et al., 2006). This literature focuses on within sector sharing or in the 'Big Data' space (Saetnan et al., 2018). Public perceptions of big data are mostly positive across western countries with negative concerns focusing on security issues (Zubiaga et al., 2018). Research in public perception is particularly noticeable within the health sector, as the development of new technology has allowed the invention of electronic health information databases that allows information sharing to occur within and between these types of databases (Canterbury District Health Board, 2013, 2017).

It is generally accepted by patients that there are significant values in and benefits to sharing health information (Howe et al., 2018). This value, however, is often dampened by the potential for misuse and other perceived risks. These perceived risks are intensified when the information shared is sensitive, such as information about physical or mental health (Whiddett et al., 2006). Howe et al. (2018) highlighted that the reluctance to share information stems from a lack of awareness around confidentiality and the procedures put in place to minimise risks. Sharing health information outside of clinician-care, however, can be a polarising issue. Patients have identified a reluctance to share medical records beyond

doctors and nurses, and this reluctance is intensified when the records contain sensitive information (Whiddett et al., 2016).

New Zealand has also delved into discovering the attitudes of individuals regarding health information sharing. This research has mostly been conducted or funded by the government and has begun discovering what New Zealanders perceive about information sharing. National Research and Evaluation Unit (2013), on behalf of IRD, identified perspectives on information sharing can be influenced by culture, while Davidson et al. (2015) discussed the attitudes toward data integration from a New Zealand perspective.

Cultural values and historical treatment by the government have played a significant part of developing many Māori and Pasifika attitudes, with research highlighting the impact of colonisation and racism in past government action as an initial distrust in organisations which spills over into trust in these organisations sharing information (National Research and Evaluation Unit, 2013). Distrust in government can be a significant barrier to consent for information sharing, especially if the information is gathered by or shared with any government organisation. The dawn raids in the 1970s exposed Pasifika throughout New Zealand to racial profiling and unethical treatment by government and New Zealand Police (Krishnan et al., 1994). While Pasifika comprised only 33% of overstayers, 86% of all prosecutions were against Pasifika (McFadden, 2015). This compares to 33% of overstayers were white (from the UK and USA), with only 5% being prosecuted, highlighting the racial inequalities in the justice and immigration departments at the time. New Zealand Police sourced this information via IRD and other government organisations and highlights how information sharing can lead to harmful abuse towards individuals and cultures.

2.9. Research questions

This research aimed to begin exploring the health concerns of children entering school with low oral language ability and investigating the appetite of teachers and parents in sharing student health information. These aims will help determine whether there is a need for increased health intervention in schools that can be facilitated through digital health information sharing.

Overarching researching questions.

What is the health profile of children who are entering school with low oral language ability?

What are key stakeholders (teachers and parents) perceptions toward sharing student health information digitally?

Research question(s) one.

What health concerns are children with low oral language ability experiencing in school, and how are their health concerns managed and perceived by their parent?

This question is addressed in chapter four, where a health profile of children with low oral language ability is established. It investigates the current levels of parent perceived health concerns of children in their first year at school, along with their engagement with treatment and past health experiences.

Research question two.

What are teachers' attitudes and beliefs regarding sharing student health information with educators?

This question is addressed in chapter five where teachers are asked about their beliefs and attitudes to establish the overall appetite of teachers and whether they would be likely to utilise student health information is it was shared with them.

Research question 3.

What are parents' attitudes and beliefs regarding sharing student health information with educators?

The question is addressed in chapter six, where parents are asked about their beliefs and attitudes to establish whether parents can see value in sharing such information and would provide consent for this information to be shared.

Chapter Three Methodology and Methods

This chapter outlines the ontological position, epistemology, design and methods employed in this thesis. It provides a rationale to why a mixed-methods approach was undertaken as well as discussing the cultural, community and ethical considerations. It also discusses the advantages and disadvantages of the methods employed. This chapter hopes to show the background and process this thesis journey took. It does not discuss the specific methods in detail; these can be found in chapters four, five and six, respectively.

3.1. Researcher position

Perceptions of most phenomena are influenced by an individual's own experiences and how they see the world around them (Creswell & Poth, 2007). As such, this research follows a constructionist ontology where reality is interpreted through individuals' experiences and beliefs. In this section, I acknowledge how I have come to form my views on this research topic, drawing on specific examples and analysing my personal and academic experiences. This section aims to provide readers with background information that explains my interest in and perceptions of this topic.

As a daughter of a teacher, my mother has often come home and lamented about how if information had been shared earlier, her teaching and behaviour management would have been different. She has often discussed the opportunity cost (as an economist would say) for valuing privacy over progress. She would highlight that if health information were shared earlier (or routinely), a child would have been better prepared to learn. I also come from a generation where computers and technology have been integrated into our everyday lives and are perceived as a tool that makes life increasingly efficient and more enjoyable. I have

knowledge (and subsequent degrees) in Psychology, Political Science and Health at the tertiary level. This academic background motivates my desire to improve the health, well-being and learning outcomes for children, and I see the sharing of health information as one approach to achieving this progress. My trust in sharing health information is influenced by mostly positive experiences with sharing documents and information for administration work (also in the health sector). My work in medical practices has displayed the advantages of sharing health information within the health sector for both practitioners and patients, advantages which, for example, have often saved patients from experiencing potentially dangerous consequences to interactions with different medications.

I want to acknowledge that my understanding of the risks of sharing private information comes from breaches in the New Zealand media (Kidd, 2019; McLeod, 2015; Trevett, 2017). Here we see examples of why control and privacy are essential to protect, and the disappointed and understandably angry response from the New Zealand public. My husband's role in the New Zealand Defence Force has taught me the importance of information security. These divided experiences and tensions have installed the interest in starting the discussion around whether sharing student health information is a good idea.

I, as the researcher and author of this thesis, believe that sharing students' health information with schools can support and help with school achievement and holistic well-being. While I think the benefits do outweigh the risks, I also believe it is essential to protect information in a way that balances the inefficiency of bureaucracy with the requirement to minimise breaches in privacy and confidentiality. I acknowledge that this view is formed through my experiences discussed above. Acknowledging these views, I have been careful to minimise the amount of researcher bias possible. When talking about the research, I always attempted

to turn the attention back to the participant or have a balanced conversation about the knowledge I had gained throughout the doctoral journey. I also made sure to validate every participant's beliefs through simple body language, verbal cues, or by showing interest in their opinion and asking them to clarify their points. By taking these steps, I enabled participants to discuss their views openly, debate with other participants and provided a safe space where all opinions and perceptions were valid.

I also emphasised the language participants used when using qualitative research methods (to minimise researcher bias in language). However, it is essential to note that, despite my best efforts and research methodologies implemented to minimise researcher bias, this research is not written by an objective and impartial individual. It is written by an individual who has a formed, yet fluid, view on the topic, that will continue to transform based on future life experiences and research data. Thus, I want to acknowledge that there is a potential bias from a positive perspective towards sharing student health information in my interpretation of the qualitative data collected and analysed.

3.2. Methodology

Scientific research frequently utilises either quantitative or qualitative research methods, although indigenous research methodologies such as kaupapa Māori in New Zealand are becoming more recognised. For this thesis, despite their different methodological underpinnings, quantitative and qualitative research methods are of interest. Quantitative methods focus on numerical and numerical-assigned data and are analysed through statistical analyses. It is employed by researchers with a positivist/post-positivist worldview, which acknowledged that "absolute truth can never be found" (Creswell, 2009). While it is thought

of as a gold standard in minimising researcher bias, quantitative research can be limited by the data that is collected and thus may miss important aspects of phenomena or information.

Qualitative research focuses on answering research questions that relate to the phenomena of complex human experiences using language-based (rather than numeric assigned) data. Researchers with social constructionist worldviews often employ qualitative methods to gather data (Creswell, 2009). Its particular strength lies in its flexibility to analyse the data. However, the typical nature and design of this enquiry mean that the results of qualitative data are often participant-specific and can be impacted by researcher bias (Holloway, 2005). With this, qualitative researchers believe their research offers some insight into the reasons for human behaviour and the experiences of individuals in particular situations. They often acknowledge their particular bias in their analysis of the data, reflecting on how the bias may impact the results, in the hope that they are minimising their potential bias on the analysis whilst also providing transparency (Qu & Dumay, 2011).

The third approach to research has been gaining momentum in the social sciences (Bourgeault et al., 2010). Mixed method research is the concept of mixing both quantitative and qualitative methods in various ways within one study. Creswell (2015) describes mixed methods as:

> *"An approach to research in the social, behavioural, and health sciences in which the investigator gathers both quantitative (closed-ended) and qualitative (open-ended) data, integrates the two, and then draws interpretations based on the combined string of both sets of data to understand research problems" (Creswell, 2015, p. 2)*

A mixed-methods approach to research follows a pragmatic worldview, as it allows for multiple philosophies to come together and to utilise data gathering through both quantitative and qualitative sources. One of the strengths of mixed methods is its fluid approach to research, allowing differing worldviews, assumptions and method to the best answer research question posed at the time (Creswell, 2009). A mixed-methods approach neutralises bias that corresponds with other methods (Creswell, 2009). By highlighting particular shortfalls in quantitative research methods, it can compensate for them by offering qualitative methods and vice versa. It also helps inform research design. In some mixed methods designs, results from one method may identify a focused research question or topic, relevant for a selected group of participants. Other methods may lay the foundation to discuss issues in greater detail (Creswell, 2009).

As with any research method, ensuring a mixed-method approach is appropriate and suitable for the research question is vital. If the approach is not suitable, the research risks yielding weak quantitative and qualitative results (Creswell, 2009). Mixed methods research can be inefficient if the results are weak, as it often requires more resources from the researcher (Giddings & Grant, 2006). It requires the researcher to have a broad knowledge of both qualitative and quantitative methods. It demands that these skills are sufficient in order to ensure both methods are being operationalised and merged appropriately. Arguably, one of the major criticisms of mixed methods research is that it has post-positivist underpinnings and privileges a post-positivist framework (Giddings & Grant, 2006). Post-positivism maintains the positivist assumption of determinism, but does so from a more complex notion, recognising that we cannot be sure about "*the absolute truth of knowledge*" when studying the thoughts and behaviour of humans (Creswell, 2009). One of the main criticisms from qualitative researchers is that researchers who use mixed-method approaches often fail to

acknowledge these underpinnings and as such, "*mixed methods covers for the continuing hegemony of positivism*"(Giddings, 2006).

Three basic designs are utilised in mixed methods research: A convergent design, where qualitative and quantitative data is gathered and analysed separately, and the results are merged to validate the findings; an explanatory sequential design, where quantitative data is gathered and analysed first and qualitative methods help explain and develop the quantitative results in more depth; or an exploratory sequential design, which qualitative methods to explore what research questions are essential and help build what the quantitative methods will investigate (Creswell, 2015). It is crucial for researchers to have a strong rationale in what kind of integration their mixed methods research will answer their research questions.

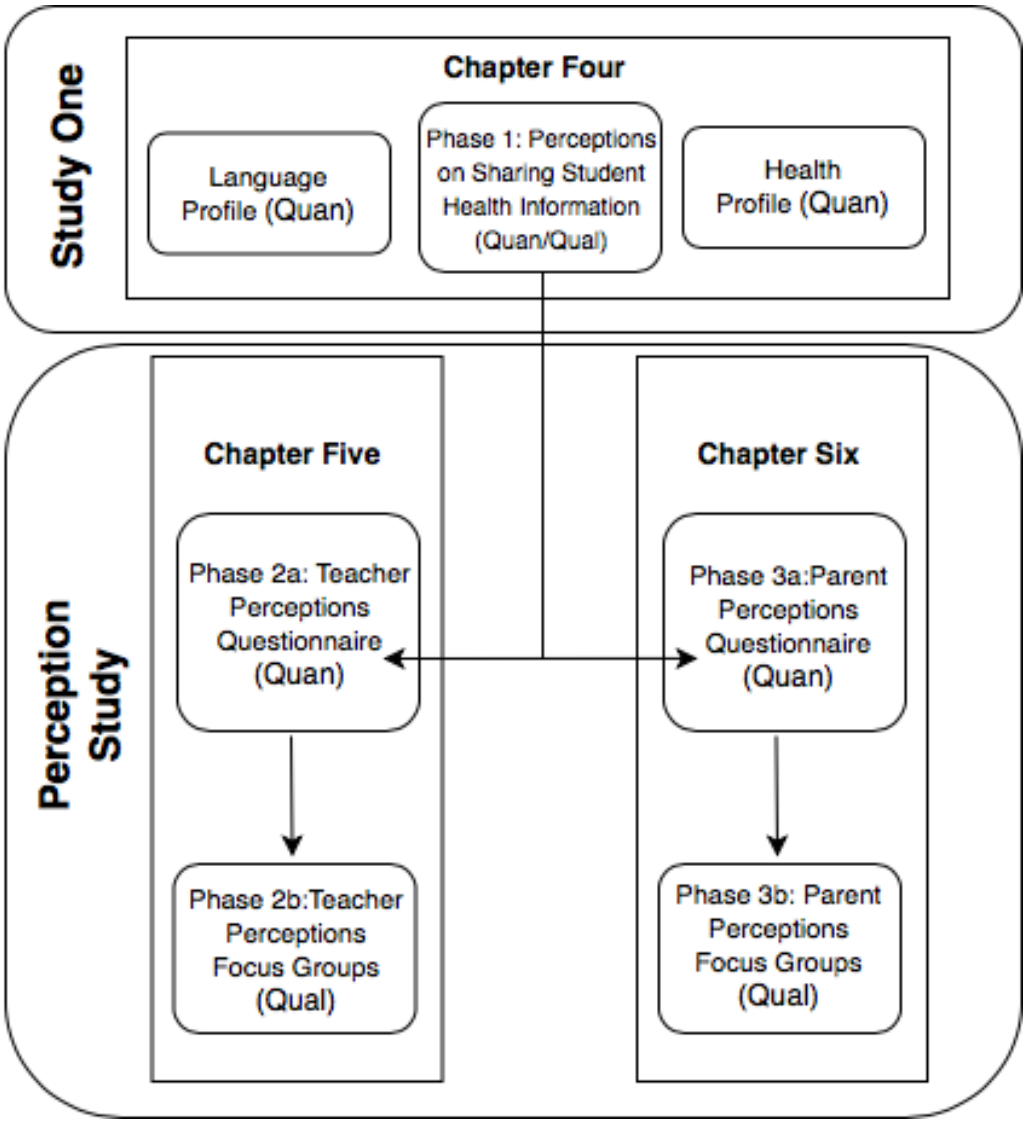
3.3. Design of thesis research

This doctoral research conducted a multiphase design. A multiphase design consists of multiple projects, of which can be quantitative, qualitative or mixed in design, and that all work toward a common purpose. The primary rationale for using this multiphase research design was the ability to build on each phase (Creswell et al., 2011). It enabled participant-led discussion around what to discuss in more detail. Themes developed in the whānau questionnaire (phase 1) informed the following in-depth perception questionnaire (phase 2 and 3). This meant that the topics were put together by whānau for whānau instead of by researchers. It also allowed for themes or topics that were bought up in the perception questionnaire to be discussed in more detail in focus groups.

This thesis is split into two central studies (see Figure 3.1) and three main phases. The first, discussed in chapter four, employs a convenient cluster sampling method to look at the health

Figure 3.1

Overview of research design



profiles of early learners identified with low oral language ability and asks parents about their beliefs in sharing student health information with teachers. While convenience sampling does not typically give generalisable results due to possible bias in data gathering and the higher possibility of sampling error (Etikan et al., 2016), the method was chosen due to its efficiency and suitable use for pilot studies, where the results informed the second and third phase method and themes (discussed in chapter five and six). The questionnaire sent to parents of

identified children was created by several members of the ABS project, giving the opportunity to include a small number of questions about health and information sharing.

The first study begins by implementing descriptive techniques delivered through questionnaires, to establish the health profiles of children who were at risk of low literacy achievement, based on their oral language ability. It looks at parent-reported health status, focussing on health concerns, illness and treatment, as well as a report of overall health. The second part of the study (phase 1) asked parents three binary questions about their opinions on sharing student health information. Using a convergent, mixed-methods study design, parents were asked to explain their binary yes/no answers to these questions. This question design began exploring the explanations into their answers, allowing participants to discuss exceptions, maximising general information, while still minimising participant burden. This design allows results to be interpreted more thoroughly than applying either qualitative and quantitative measures and gives more detailed information to why differences exist between participants.

The perception study (phase 2) builds on the findings of phase 1, using the themes found for discussion in two questionnaires for teachers and parents, specifically to gather more in-depth information about parent and teacher perception on sharing student health information with schools and teachers (phase two). It uses another convenience cluster sampling method, investigating three Christchurch primary schools with purposely selected different decile ratings (more about these individual schools and their decile ratings can be found in chapter 5). The perception study uses sequential explanatory mixed methods, using the more specific questionnaires in phase two to inform the follow-up focus groups (conducted in phase three). The data obtained in phase two was analysed first, and based on the themes and points made

in these questionnaires, a semi-structured focus group schedule was developed. This was to ensure critical subjects that came up in the questionnaires were discussed with participants, however, allowed for the participants to go on relevant tangents if they wanted.

3.4. Overview of methods

Quantitative methods

Two base questionnaires were used in this study (the whānau questionnaire for phase 1 and the perception questionnaire for phase 2 and 3). All questionnaires were available to participants in hard-copy or online. The whānau questionnaire aimed to gather preliminary data from a convenient sample of parents whose children were identified as having low oral language ability. The data allowed the researcher to establish a health and language profile on these children, and pilot three specific questions around health information sharing that could be used in phase 2 and 3. The second questionnaire was used in the perception study and was modified slightly depending on the participants it was targeted towards (teachers or parents; phase 2A and 3A respectively). The survey was primarily quantitative, allowing participants to tick common answers identified in phase one. The majority of questions also allowed participants to add comments to their answers if they wanted to. These questionnaires aimed to develop a much more in-depth view of sharing student health information and inform the talking points for the semi-structured focused groups in phase 2B and 3B.

A variety of quantitative statistics were utilised in all three questionnaires to analyse differences between participant schools and roles. These statistics included an analysis of variance (ANOVA) for comparing participants ages between schools and roles at school, Fisher's exact test (FET) to test for independence with categorical variables (roles of school staff and schools) and analyse the Likert scale in phase 2A and 2B. Cohen's Kappa measured

agreement between information that would assist a teacher's ability to teach and what information teachers would be comfortable accessing in phase 2A. SPSS25 was used for all quantitative analyses (IBM Corp, 2017) and significance for all tests was at p=0.05. Reporting of quantitative methods were informed by the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines.

Qualitative methods

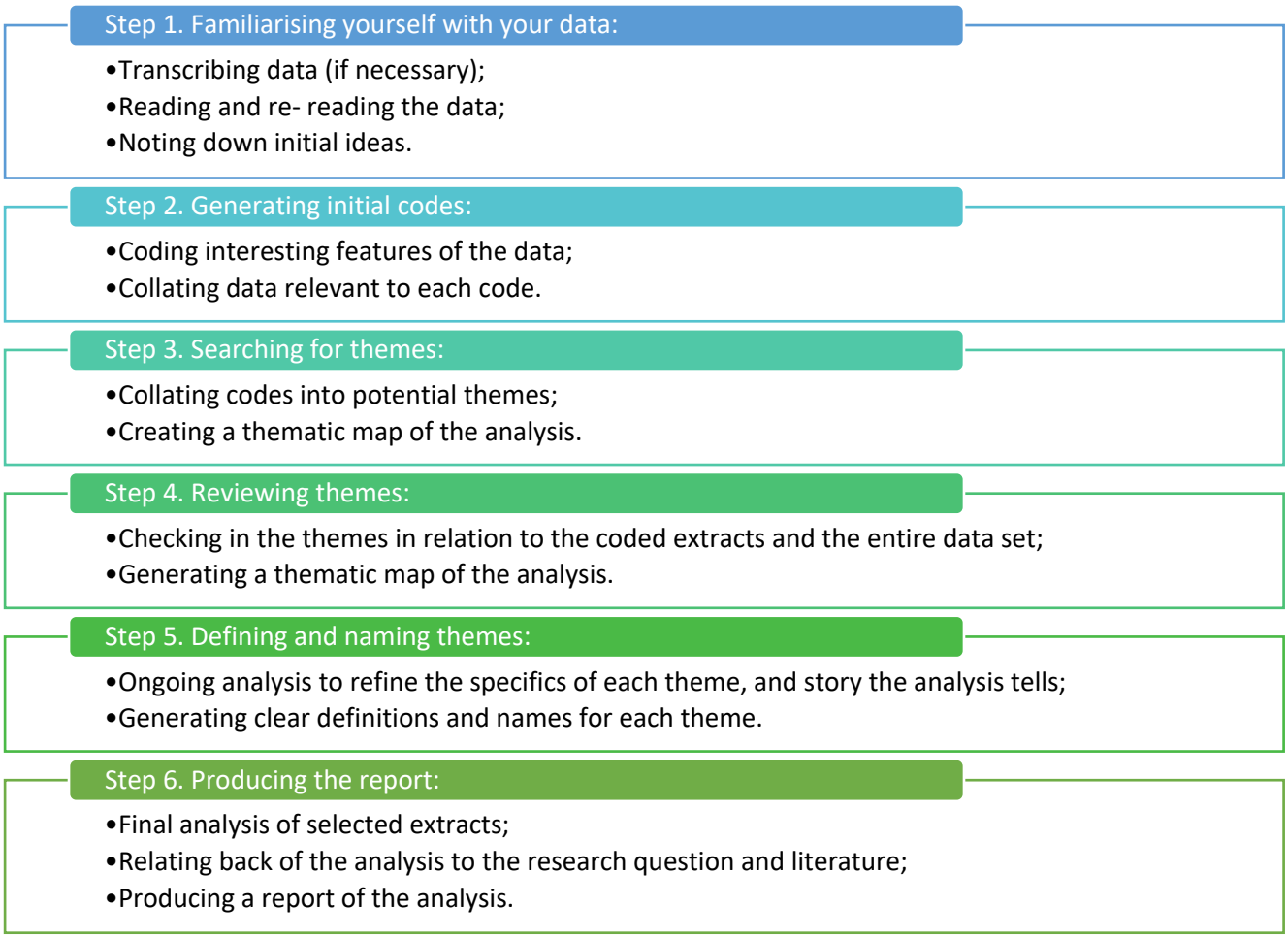
The qualitative research for this thesis was designed following the quantitative questionnaires (phase 1, 2A and 3A) to gain better insight into participant's perceptions around health information sharing. Qualitative data was collected from explanations of answers on the questionnaires (phase 1) and semi-structured focus groups were employed in phase 2B and 3B of the research. These focus groups enabled the researcher to build on the results of the phase 2A and 3A questionnaire. They allowed more specific discussion, particularly around areas of contention and in confirming areas of high agreement. The focused groups were semi-structured, and the schedule used was put together with the results from phase 2A and 3A. The focus groups allowed participants to link their own experiences to their beliefs, explain their views, bring up areas that were not included in the questionnaires, and openly discuss concerns about sharing.

All three phases utilised thematic analysis in examining the qualitative data gathered. Braun and Clarke's (2006) six steps of thematic analysis provided a guideline for an inductive approach to thematic analysis, where themes were identified directly from the data rather than to fit a pre-existing coding frame. Figure 3.2 describes each of the six steps utilised in thematic analysis process across all three phases. These six steps allowed the data to form a narrative of participant perceptions of sharing student health information that goes:

"... beyond description of the data, and makes an argument in relation to the research question" (Braun & Clarke, 2006).

Figure 3.2

Steps of the thematic analysis process



To ensure the thematic analysis was conducted in a rigorous manner, interrater reliability was employed. Disagreed coding or theme placement was discussed until 100% agreement is attained. The Consolidated criteria for reporting qualitative research (COREQ) guidelines were utilised in the reporting of qualitative analyses (Booth et al., 2014; Tong et al., 2007).

3.5. Participating schools

Teachers and parents of children in their early education years (first two years of school, years 0-1[10]) from three schools located in the Canterbury, New Zealand area were asked to participate in Phase two and three of the study. Schools were asked to participate through existing relationships with university staff, through participation in ABS literacy intervention programme.

School A

School A was chosen due to its progressive views and interaction with government health organisations. School A sits as a decile one school rating, putting it in the highest funding bracket for complex needs. The school also has a high number of Māori students, with over 45% of students identifying as Māori in 2017. It incorporates a modern learning environment and caters to students in school years 0-15. Its higher-than-average number of students with complex (learning, health and social) needs, paired with its progressive technological resources made it an especially interesting participating school in this research. Reflective of its technological progressiveness, the school relied heavily on information sharing practices and as such, had developed its own information management, data and applications principles (as discussed in chapter two). These principles were developed with the New Zealand Privacy Act 1993 and Education Act 1989 as guiding legalisation, with one of the 30 principles developed ensuring all data management, use and sharing complied with New Zealand law. When reading through them, the NZDFF four principles of trust, control, value and inclusion were able to be incorporated (for example, "*Data is an Asset*" incorporates the

[10] New entrants in New Zealand are referred to as either Year 0 or Year 1 (Ministry of Education, 2020b)

value principle developed by the NZDFF). School A also allowed us to utilise their community, school and technological networks in the distribution of parent questionnaires.

School B and C

Both School B and C were asked to participate in this research through their involvement to the literacy intervention lead by ABS. School B was located in a middle decile area and had a vast breadth of ethnicity (27% NZ European, 8% Maori, 7% Pasifika, 45% Asian, 11% Other). It allowed for the inclusion of participants of various ethnicities, aligning with New Zealand's growing multi-cultural population. School C was located in one of the affluent areas in Canterbury, holding a decile rating of nine. Its population make up was mostly of NZ European families (67% NZ European, 17% Maori, 2% Pasifika, 11% Asian, 4% Other). Neither school had a specified policy for sharing information about a student instead opting to follow the appropriate national legislation required for all schools.

3.6. Research values in Aotearoa, New Zealand

Any research conducted in New Zealand must consider the Treaty of Waitangi - Te Tiriti o Waitangi. The Treaty of Waitangi is the founding document of New Zealand, signed by approximately 540 Māori Chiefs and leaders in 1840 (New Zealand History, 2017). It is an integral document enshrined in New Zealand law. It has three fundamental principles embodied in the document, namely: partnership, participation and protection of the Tangata Whenua (indigenous Māori people). Within research, these principles involve developing partnerships and relationships with participants (Macfarlane & Macfarlane, 2012), and involving Māori in research design (Bevan-Brown, 2003). The principles of partnership and participation are vital to this research, as it aims to consider the perspectives of New Zealand parents and teachers on health information sharing and to create a system in partnership with

them. The research follows the bicultural pedagogy of New Zealand's education system, which is based on the implementation of the Treaty within schools (D'Cunha, 2017).

It is vital to include key stakeholders in the design, development and implementation of a novel information sharing system. Any information sharing within New Zealand (and arguably outside of New Zealand) requires deep levels of trust, robust protection and consider how to minimise any harm or risk of further oppression of indigenous cultures. For Māori, this is particularly important as Māori data is considered living taonga (highly prized/treasure) and requires Māori sovereignty and governance (Te Mana Raraunga - Māori Data Sovereignty Network, 2016). This research must be guided by Māori consultation to ensure that any information sharing is culturally acceptable and appropriate.

Cultural considerations to research design and method

Consultation with Adjunct Associate Professor Sonja Macfarlane of the University of Canterbury Child Well-being Research Institute was undertaken as per ethics recommendations, and her support continued throughout the doctoral journey. Associate Professor Sonja Macfarlane affiliates to the Ngāi Tahu and Ngāti Waewae iwi (tribe) in the South Island of New Zealand. She is an integral part of the ABS project and guides the project as our Māori advisor. In this consultation, Associate Professor Macfarlane highlighted the need to prioritise relationship-building with participants, and that the questionnaire included te reo Māori (the Māori language). She also suggested incorporating Māori researchers for cultural support and advice, and ensure that focus groups were in a culturally safe environment that would empower participants to discuss their views through their cultural lenses. After the initial consultations with Associate Professor Macfarlane, the questionnaire was examined for cultural appropriateness, te reo incorporated, and a plan

made to have the researcher present most days in the school environment when data collection was occurring and occasionally before and after at cultural events. Associate Professor Macfarlane and fellow ABS PhD candidate, Dr Melissa Derby (Ngāti Ranginui) gave their support and examined the research methodology through their unique Māori perspective.

There was an emphasis on ensuring the researcher shared research findings and contributed to advancing knowledge with the community. Dissemination and relationship-building with participants and their communities was a vital component of cultural considerations. This dissemination was to be done at different stages through the analysis, ensuring that participants were up to date with any findings. The researcher also engaged in activities within the school communities. These activities included assisted school leaders in health funding applications to support their complex students, providing afternoon tea for staff and parents, and assisting teachers on school trips and school cultural evenings. These interactions helped to build trust and respect and to become known within the community (Best Practice Advocacy Centre New Zealand, 2008).

3.7. Important considerations

The regional context of this research

The following studies take place within Christchurch City, Canterbury, New Zealand. In 2010 and 2011, the Canterbury region experienced two major earthquakes. The first occurred at 4.35am on the 4th September 2010, 40 kms east of the city. The second earthquake occurred on the 22 February 2011 at 12.51pm, centred only 6kms southeast of the city. While both earthquakes caused significant damage to buildings and infrastructure around

Canterbury, the February earthquake resulted in the loss of 185 lives, with approximately 7,171 people injured (Potter et al., 2015).

These earthquakes caused significant mental health harm for those residing in Canterbury at the time. As a result, the trauma of experiencing a natural disaster had a significant impact on mental well-being throughout the district, with many young children suffering from increased levels of anxiety. The trauma of the earthquakes was perpetuated by over 14,500 aftershocks since the September 2010 earthquake (Morton, 2015). Teachers in the area have noticed the impact of the earthquakes in the school setting, with mental health support services in the area over-burdened and these services having exceptionally long waiting lists as a result (Liberty et al., 2016). Over eight years since the first earthquake, the region is still experiencing the impacts of trauma. There are still large waiting lists for mental health services, and the city regeneration is nowhere near complete. Due to the overburden on mental health services, many Canterbury teachers are responding to their students' mental health needs (Johnson & Ronan, 2014).

The earthquakes highlighted the need for more electronic systems in health services and health information sharing, particularly in the family physician services. Due to a large number of injuries and loss of life caused in the February earthquake and damaged buildings that could not be accessed, many health professionals were unaware of patients' previous medical histories and records. These records were unavailable as many GP's were unable to return to their practices to access physical records to share this information with hospitals, causing delays in treatment, poor health management and medication contra-indications (Ardagh et al., 2012). As a result of medical record inaccessibility post-earthquake, the CDHB restructured their data sharing services, with the implementation of the system

HealthOne. HealthOne is an online platform which allows notes from hospitals, test results, GP summaries, and medications to be accessed by health professionals (for more information, see chapter 2). This flexibility given to the CDHB following the earthquakes allowed them to take an accelerated and progressive approach to re-envisioning the future of health care (Gullery & Hamilton, 2015). As such, the CDHB and other organizations in the Canterbury region have a culture for being open to and taking on progressive projects within its health and education sectors.

Another important consideration is the Mosque attacks in Christchurch experienced on the 15th March 2019. Progressive information sharing policies are often a response to terrorist attacks, as governments emphasise the need to share and access information to keep citizens safe, and creates a precedent that security trumps liberty (Dornan, 2011). These attacks may have changed parent perceptions of information sharing in general, as the need to share information was emphasised in the media. As these attacks occurred halfway through Phase 3's data collection phase, they did have an impact on this particular phase method, as well as the potential for impacting the findings of phase 3. The impact of the 15th March attack is discussed in more detail in chapter 6 and 7.

Community relationships

Some of the sentiments of the ABS project included the emphasis of walking alongside communities, building relationships with whānau, and contributing to communities in a positive and meaningful way. As a result, the researcher prioritised relationship-building with kaiako (teachers), and senior staff in the schools visited. Relationships with schools whose parents participated in the whānau questionnaire discussed in chapter four were established through members of the ABS project.

This research had teachers and parents from three different schools participate. Two of the three schools were included in the ABS project, with relationships being built by multiple researchers in the project. The researcher was also invited to these two schools to introduce herself during a meeting that disseminated a preliminary report of how the ABS project had worked in their school so far. The final school was identified through relationships of researchers at the University of Canterbury, ABS project, the CDHB and a member of the school board. The researcher was invited to meet with a senior management member to discuss this research and whether the school was interested in participating.

An essential part of relationship building with this school was the researcher ability to work with them to receive extra funding for teaching support. The researcher completed ten case studies of children from various backgrounds and made a case for extra funding for the school and these children. The researcher was also invited to observe the year 0-2 staff meetings, where teachers and teacher aides discussed children they were concerned for (due to their behaviour, achievement, or family situations). By observing these meetings, and writing up the case studies, the researcher built lasting relationships with the staff, while also gaining a better understanding of the school ethos and passion for students. (Potter et al., 2015).

3.8. Ethical considerations

All data collected as a part of this thesis received ethical approval from the University of Canterbury's Educational Research Ethics Committee. Two approvals were given, the first was included as part of the larger ABS project (2016/21/ERHEC) and approved the whānau questionnaire discussed in chapter four (see Appendix B.1). The second and final approval

was applied for separately (2017/50/ERHEC) and gave approval for the questionnaires and focus group interviews discussed in chapter five (see Appendix B.2). The second application highlighted the need to build relationships with schools and parents through culturally and community responsive actions, with an emphasis on ensuring the research was presented back to schools, both in a written format but also in person at presentations to school staff and whānau of school students.

Multiple amendments to this approval were made, one of which was the rewording of the consent and information sheet for questionnaires. This particular amendment occurred after feedback given by teachers from School A who suggested the language and quantity of writing was inappropriate and needed to be simplified so that parents could understand the content better and not be deterred from completing the questionnaire. Other amendments included: having questionnaires accessible online through Qualtrics TM (www.qualtrics.com), adding two schools with differing decile ratings (more on this in chapter five and six), additional questions added to ensure participants meet criteria, additional answers added to questions to allow more "tick box answers", removal of questions that were no longer relevant (e.g. child's general practitioner), and allowing an online transcription company REV (www.rev.com/transcription) to transcribe two of the five focus groups due to time constraints (despite this amendment the researcher transcribed all of the focus groups).

3.9. Summary

This chapter discussed the position of the researcher, the theoretical underpinnings and methodology that informed the research design and methods employed to explore the aims of this thesis. The methodology used was based on the pragmatic paradigm, however, also drew

on constructionist epistemology. It allowed quantitative and qualitative data to be explored and analysed appropriately and allowed participants the chance to explore, question and explain their perceptions around sharing health information. The chapter also outlined the ethical, community and cultural considerations that moulded this research.

Chapter Four Phase One: Health Profile of Children with Lower Oral Language Ability & Pilot of Data Sharing Attitudes

Children who enter school with lower levels of oral language are known to be at heightened risk for adverse life outcomes (Awan et al., 2011; Dewalt et al., 2004; Literacy Foundation, 2018). Catts et al. (2001) reported that preschool children in the USA who had language impairment were 4 to 5 times more likely to have literacy difficulties (and associated educational problems) than children who enter school with age expected or advanced oral language skills. It is essential to understand whether these children have additional health issues that may further impede their learning and literacy development. This understanding will help consider and support all aspects of the child's well-being appropriately to ensure more positive life trajectories for these children.

Hearing and vision are vital tools in decoding and letter-sound knowledge, while behaviour concerns and absenteeism mean valuable teaching hours are lost (Thies, 1999). Hearing difficulties are linked to increased behaviour concerns, higher levels of stress, poorer self-esteem, struggles in mental well-being and difficulties in creating meaningful social support systems with their peers (Bess et al., 1998; Bess & Tharpe, 1984; Stevenson et al., 2015). Young people with permanent hearing loss are at significant risk of not developing adequate literacy skills (Kushalnagar et al., 2010; Lederberg et al., 2013). Hearing loss or difficulties can have a significant impact on PA development, especially in early schooling (Briscoe et al., 2001). PA is a key predictor of early literacy development (Gillon, 2017). It refers to an individual's knowledge of the sound structure of language and the skill to hear and break words into different sound units (e.g. syllables, rhyme, and individual sounds or phonemes). Children entering school with low levels of PA are at higher risk of low literacy and reading

ability (Carroll & Snowling, 2004). Children with language impairment or lower levels for oral language ability frequently demonstrate poor PA ability (Gillon, 2017). Similar to hearing, lack of visual acuity can have significant impacts on literacy development and the ability to gain orthographic knowledge essential for literacy learning (Boets et al., 2008; Bruce et al., 2016). Between 5-10% of children experience visual concerns as pre-schoolers (Wang et al., 2011), which if left untreated, can result in poor literacy outcomes in early schooling (Hopkins et al., 2017).

The impact of low literacy can impact overall academic ability as literacy skills are a vital component through all areas of the school curriculum (Schluter et al., 2020). Low literacy skills can lead to significant learning difficulties which can exacerbate the impacts on academic achievement (Duncan et al., 2007). Children with learning difficulties often find themselves being bullied and struggling to establish supportive peer relationships (Nabuzoka, 2003). If a child is unable to engage with learning, they may find themselves acting out of boredom or frustration, which can transform into poor behaviour in the classroom.

Adelman and Taylor (2006) discuss the learning barriers students can often face in the classroom, which can impact student behaviour and achievement. These include a range of factors, both external and internal of the school and classroom environment. They highlight how internal factors (such as health, vision and hearing problems) can lead to children disengaging in the classroom. This disengagement may manifest in behavioural concerns observed by teachers and parents and thus could explain why a high number of participants have concerns with their child's behaviour.

This chapter considers the physical and emotional components of well-being in early learners first by establishing a parent-reported health profile of learners who entered school with lower levels of oral language ability. These findings give insight into the health of early learners who can be identified as at risk of low literacy due to low oral language ability and establishes whether this sample of early learners has experienced health conditions that may have impacted their learning success. It then discusses the parental perceptions of sharing health information as a potential tool and intervention strategy to improve support for early learner's well-being and contributing to the multi-faceted approach to improving academic success.

4.1. Phase 1 aims

There are two primary aims of phase one: to establish parent-reported health profiles of early learners identified with low oral language ability; and, discuss with these parents their perceptions of sharing student health information with schools and teachers.

4.2. Methods

4.2.1. *Study design*

This cross-sectional study looks at the health profile of learners identified with low oral language ability by using convenience sampling methods. It takes a constructionist descriptive analysis. The study incorporates aspects of grounded theory, where it seeks to establish the thoughts and beliefs around sharing student health information of a convenience sample of parents of children who were identified as having lower levels of oral language ability. It utilises a quantitative and qualitative data derived from a questionnaire (named the

whānau questionnaire), that asks participants their views on sharing student health information with teachers.

4.2.2. *Participants*

Seven low decile primary schools that were impacted by the series of Canterbury earthquakes in 2010 and 2011 were selected to participate in this project, with all agreeing to partake. These schools were all part of a kāhui ako (community of learning) which was developed after the earthquakes to better their students' education outcomes and agreed to participate in the ABS intervention (Gillon et al., 2019). To be eligible for this study, participants were parents of students undertaking their first year of schooling at seven schools who were identified as entering school with lower levels of oral language ability. Learners with lower levels of oral language ability were identified utilising the recalling sentences subtest from the Clinical Evaluation of Language Fundamentals – Preschool 2 (CELF-P2; Semel et al., 2006) and the initial phoneme identity task from the New Zealand Computer-based Phonological Awareness Database (CBPA; Carson et al., 2011). All children who attended the seven selected primary schools were screened as a part of their regular school instruction. Children were selected to participate if they scored seven or below on the CELF-P2 subtest or if they scored five or below on the CBPA assessment. Parents were asked for consent for their and their child's participation in this study. An in-depth language assessment was conducted on all consented children after the two initial screening tests to confirm the children's lower level oral status (Gillon et al., 2019). All participants were selected using a convenience sampling technique.

4.2.3. *Materials*

Parent(s) or guardian(s) of the eligible participants were asked to read an information sheet about the research and fill in a whānau questionnaire along with a corresponding consent form and information sheet (Appendix C.1). Team members of ABS developed the whānau questionnaire: E Tipu E Rea. Associate. Professor Sonja Macfarlane (who acted as a Māori advisor for this research) championed questionnaire development and employed a mana enhancing approach based on core Māori cultural values. Questions were submitted by several members of the project to answer multiple research questions. Based on these questions, the questionnaire was split into five sections that spread over twelve pages (demographics, hauora - health and well-being, hononga - reading together at home, hinengaro - reading practices, harikoa - positive identities). Answers from the demographic section and section one hauora were analysed for this study. These sections made up the first five pages of the whānau questionnaire and covered questions around physical health, sleep, behaviour and speech, literacy, language and hearing. Researchers from ABS project analysed data gained from other sections of the whānau questionnaire for other research purposes.

The demographics section asked participants about their child, including gender, date of birth, ethnicity, and relationship to their child. In the case where multiple ethnicities were recorded, a researcher asked the participant which ethnicity they identified with most, and this was the ethnicity reported (no participants were unable to give a preferred ethnicity). The hauora section discussed areas of health concern, whether their child had received any medical treatment, their child's overall health, sleep and behaviour and language and several questions asked about speech, literacy, language and hearing. These questions put together a health profile of the children who were identified as entering school with lower levels of oral

language ability (the first aim). Where possible, questions in this health profile were adapted from other established instruments with psychometric properties such as the SDQ. For example, our questionnaire asked, "*based on your child's behaviour over the past 6 months, how do the following apply: Is considerate of other people's feelings?*" and allowed parents to answer "*mostly, sometimes, hardly ever, or never*". This question is similar to the SDQ which asks parents *"…on the basis of the child's behaviour over the last six months, a) considerate of other people's feelings*" and allows parents to answer "*not true, somewhat true or certainly true*" (Goodman et al., 2004).

Questions about health information sharing were also purposefully developed by the author of this thesis and included to investigate the second aim. Two of these questions asked, "*Do you think that a teacher should have access to a child's medical/health records? Please explain your reason(s) for your choice:*" (teacher access question) and "*Do you think that teacher awareness about a child's medical/health information is important to the teaching and learning that happens at school? Please explain your reason(s) for your choice:*" (teacher awareness question). Two choices were given for each question ("*yes*" and "*no*") along with space to explain their choice. The third question about health information sharing in the whānau questionnaire asked "*Whānau/family/aiga/caregiver consent for a teacher to have access to a child/s medical/health records should be*". Participants could choose from one of two answers; either "*automatically given as part of the school enrolment process*" or "*given only when a request has been made for health data to be released*" (consent question).

4.2.4. *Procedure*

The whānau questionnaires were sent out via teachers, with participants given a choice to fill out the hard copy and return it via the student's teacher or school (which was collected from

there by the researchers) or to complete the questionnaire online through the Qualtrics program (Qualtrics, 2018). Researchers encouraged parents to complete the questionnaires through a variety of measures. Participants were offered the opportunity to access one-on-one support from ABS researcher either at their home or at community workshops run by ABS project for literacy development in east Christchurch. Researchers also contacted participants during the follow-up process, with some questionnaires being completed primarily over the phone, or via email. To do this follow up, researchers used contact information given by participants. They went through those who had not completed the whānau questionnaire and had provided contact details on their consent forms.

4.2.5. *Ethics*

Ethical approval for this study was given by the University of Canterbury's Educational Research Human Ethics Committee (refer to chapter 3.8 for further information). With this approval, consent forms and information sheets (Appendix C.1) were given to all parents, with separate information sheets and consents being available to children (Appendix C.2). An additional consent and information forms were given to participants who were eligible to complete the whānau questionnaire (Appendix C.3). Participants were able to withdraw at any time.

4.2.6. *Data analysis*

To determine whether those that responded to the questionnaire were similar in demographic characteristics to those who did not respond to the whānau questionnaire, an independent sample t-test was run. This t-test looked explicitly at the language profile of responders and

non-responders, utilising the CELF-P2 and CBPA screening tools, allowing inferences to be made about whether the responders were representative of the sample.

Establishing a Health Profile – Aim One

To create a descriptive health profile for the sample of children, the first step in this analysis was to examine the frequencies of health concerns and illness in the last 12 months. This step identified common illness and areas of concern. Once areas of concern were identified, the researcher was able to look at whether health concerns were managed with appropriate treatment and services. Other variables examined included comparing parental health rating and illness in the past 12 months, the consistency between concerns of sleep and behaviour with reported sleep and behaviour patterns, and finally the consistency of speech, literacy and language concerns with professional help for speech, literacy and language sought. This descriptive data developed a health profile of children from seven primary schools, who entered school with lower levels of oral language ability.

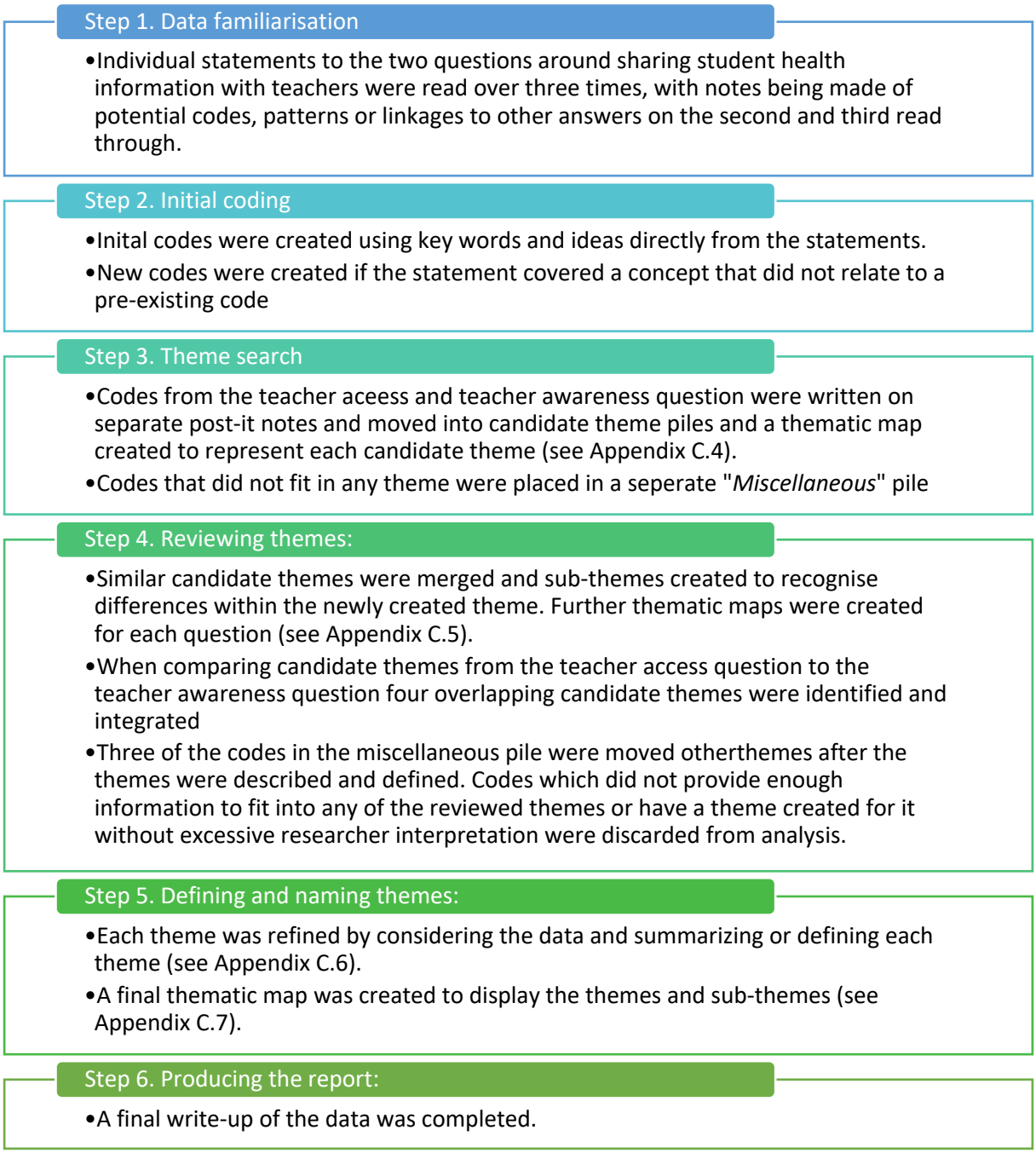
Parents' Perceptions of Health Information Sharing

A mixed-methods approach was employed to look at the data regarding parent perceptions of student health information sharing. Quantitative analysis included frequency analysis of the teacher access, teacher awareness and consent questions to show the general agreement or disagreement between parents. A qualitative approach through thematic analysis was then employed to look into the reasons and explanations for answers to the teacher access and teacher awareness questions. Explanations given to the teacher access and awareness questions were examined applying thematic analysis using Braun and Clarke (2006) six steps to thematic analysis as described in methodology chapter 3.4. Figure 4.1 displays the process of each of the six steps taken for this analysis. No names were used to ensure anonymity and

confidentiality. To add to the thematic analysis around perceptions of sharing student health information, a question around how consent is obtained, asked and examined.

Figure 4.1

Process of thematic analysis for phase 1



Interrater reliability was conducted on three open-ended questions discussed in this study (teacher access, teacher awareness and consent questions) to ensure a rigorous approach to

thematic analysis. The author initially coded the statements, with a colleague having the list of codes created by the author and matching them to the statement. The percentage agreement was 94%. The disagreed codes were discussed until 100% agreement was attained.

4.3. Findings

All children in their first year of schooling (ranging in ages from 5 years and 0 months to 5 years and 11 months) from these schools (n = 247), were screened to identify learners with low oral language ability. Following the screening, 170 (69%) children were identified with lower levels of oral language ability and eligible for participation. Of those eligible, parents of 152 (89%) children consented to participate, with 43 children identified as having low initial phoneme identity performance on the CBPA assessment, 45 children were identified with low oral language performance on the CELF-P2 tests, while 64 children were identified as low on both screening tools (Gillon et al., 2019). Of the original 152 children, 11 (7%) children left after the study commenced, none of whom filled in the whānau questionnaire. Parents of 141 children were asked to complete the whānau questionnaire. Eighty-five (60%) parents returned their questionnaire (see Figure 4.2 adapted from Harris et al. (2018). This response rate highlighted the success of the methodological approach in this study, especially when compared to the response rates in low SES of 36% in Claudio and Stingone (2008).

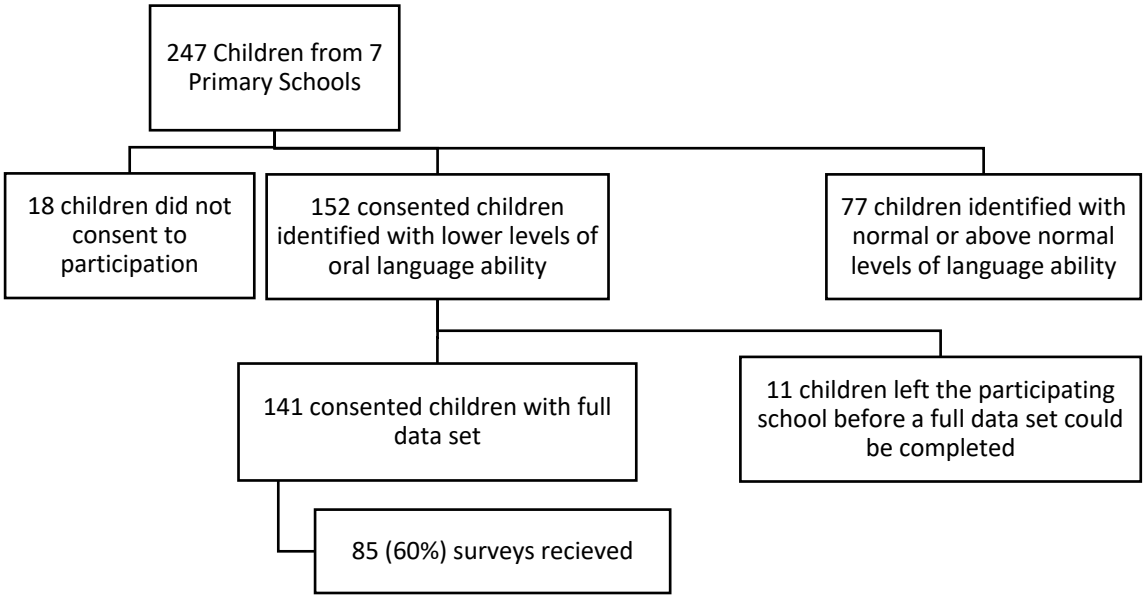
4.3.1. *Questionnaire participant demographics*

The returned questionnaires consisted of parents and guardians of 85 new entrants, primary school children (50 boys, 35 girls) with low oral language abilities (mean age of 5 years and four months). The majority of participants were mothers (58%), with seven fathers (8%) and four other whānau members (5%) participating. Twenty-five (29%) participants did not identify their role to the child with low oral language ability. Table 4.1 outlines the

demographics of the 85 children. There was a high proportion of Māori (27%) and Pasifika (18%) children in this sample when compared to New Zealand population of 5-6-year-olds living in the Christchurch area (8% and 3% respectively; Statistics New Zealand, 2013).

Figure 4.2

Visual representation of recruitment process



Adapted from Harris et al. (2018)

4.3.2. *Language and health profile of learners with low oral language ability*

Of the 85 questionnaires returned, 76 (89%) children had full language and literacy datasets collected. Of those 76 children who had a full language set and a whānau questionnaire, 24 (32%) were identified as experiencing a speech difficulty, compared to 16 (24%) children whose parents did not respond to the questionnaire. There was no difference between those who completed the whānau questionnaire based on those identified with a speech difficulty (FET, $p = 0.27$). In comparing multiple measures that contributed to the language profiles of children, no significant differences between responders and non-responders were found ($p < 0.05$; see Table 4.2).

Table 4.1

Characteristics of 85 children identified in phase 1 compared to StatsNZ [a] national data

Characteristic	Whānau Questionnaire Age 5-6 years		StatsNZ data Age 5-6 years	
	n	(%)	n	(%)
Gender of Child				
Boy	50	59	65,331	51
Girl	35	41	62,367	49
Ethnicity of the Child [b]				
NZ European	44	52	84,621	66
Māori	23	27	34,520	27
Pasifika	15	18	18,048	14
Asian	12	14	21,387	17
Other	5	6	4230	3

[a] Population data provided by (Statistics New Zealand, 2018)

[b] ethnicity includes every option ticked, thus some children had multiple ethnicities.

Table 4.2

Means, Standard Deviations and p-value for the Language Profile Measures

Measures	Responders (n=76)		Non-responders (n=67)		p-value*
	M	*(SD)*	*M*	*(SD)*	
Letter-sound knowledge [b]	10.0	(5.3)	10.5	(5.7)	0.60
Phonological Awareness Total [b]	11.4	(5.6)	12.1	(6.3)	0.45
Core Language Score (scaled)[a]	84.3	(15.1)	82.8	(17.4)	0.57
Language Structure Index [a]	83.3	(15.6)	81.5	(16.7)	0.50
Expressive Language Index [a]	82.8	(14.3)	80.4	(15.7)	0.34
Non-word reading (Calder, 2000)	4.5	(6.1)	4.3	(5.7)	0.88
Receptive Vocabulary (raw)[a]	11.3	(2.9)	11.3	(3.0)	0.89
Expressive Vocabulary (raw)[a]	2.8	(2.6)	3.0	(2.5)	0.58

Note: [a] CELF-P2 subtest (Semel et al., 2006); [b] CBPA subtest (Carson et al., 2011);

*calculated using t-test

Of the 85 questionnaire responses, there were 84 valid responses to question two regarding any possible areas of health concerns for their child. Of these responses, 46 (55%) participants noted that they have or have had concerns with their child's health, with 22 (69%) NZ European children, 7 (47%) Pasifika children, 14 (61%) Māori children, and 2 (20%) Asian children having whānau-identified concerns with one or more areas of health. When comparing ethnicity, no significant differences were found (FET, $p = 0.08$).

Parents were most concerns with behaviour (19 responses), followed by hearing and learning concerns (16 responses each). Other areas of concern, such as vision, speech, and sleep, were also recorded (see Figure 4.3). Of the 46 participants who had concerns for their child's health, 25 (54%) recorded more than one health concern, with 7 (8%) participants noted two concerns, 10 (12%) participants noted three and 8 (9%) noting four or more concerns.

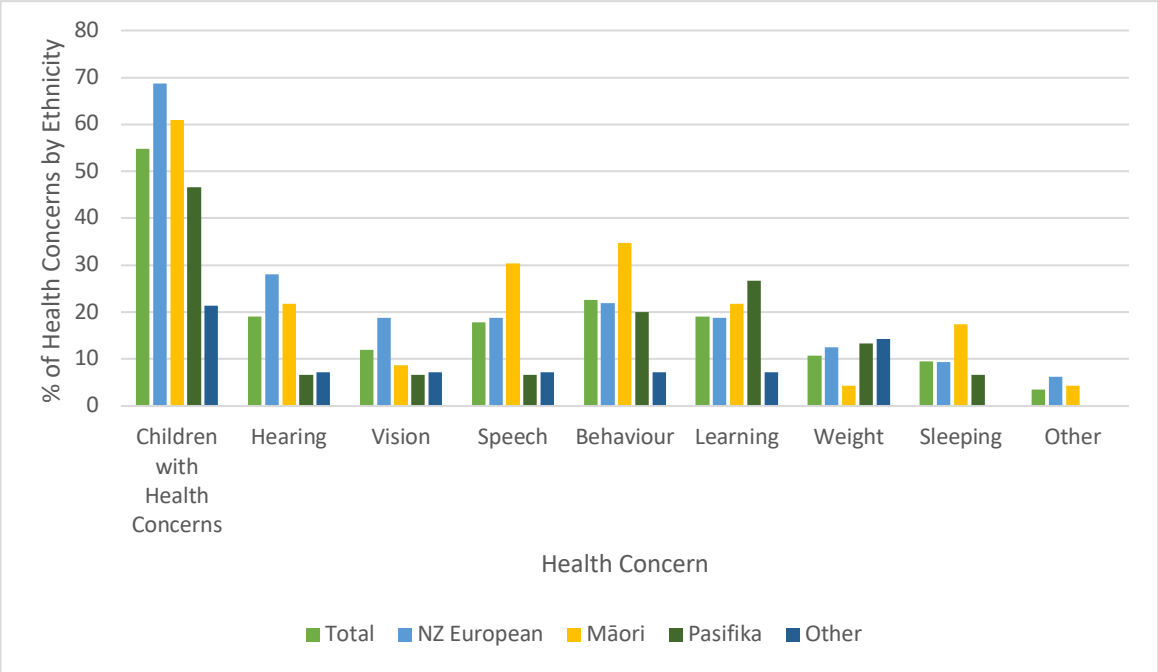
When matched with the language profile[11], 59 (79%) parents correctly identified their child having a speech difficulty (10 children) or not having a speech difficulty (49 children). Parents of 14 (19%) children who had a professionally identified speech difficulty had no concerns with their child's speech. Participants also were unable to correctly identify their child's speech difficulty ($\kappa = -0.09$ (95% CI, -0.15 to -0.03), $p < 0.01$).

In terms of common childhood illnesses, 42 (50%) children experienced a common childhood illness in the past 12 months. Asthma impacted 23% of children in the past 12 months, while

[11] To compare language profile, parent-reported concerns with speech was compared with the clinically identified speech status conducted in Gillon et al. (2019). Ten answers were missing (incomplete dataset).

Figure 4.3

Percentage of health concerns in new entrant children entering school with lower levels of oral language ability.



eczema or dermatitis and earache or infections impacted 20% of children, respectively. These three illnesses stood out in terms of their frequency when compared to other illnesses discussed, such as chest infections, throat infections and food allergies (see Figure 4.4).

A total of 39 (46%) parents stated their child had received treatment for health concerns. Of that, 17 identified as NZ European, 12 identified as Māori, and five identified as Pasifika. No significant differences were found by ethnicity in whether the child had sought treatment ($p = 0.40$). Surgical and medicinal treatment was the most common, with 19 (23%) participants stating they had received these forms of treatment (see Figure 4.5). More NZ European children (25%) received grommets for their hearing problems (FET, $p=0.05$) than children identifying as Māori (4%), Pasifika, Asian or other (0%).

Figure 4.4

Percentage of common childhood illnesses in new entrant children entered school with lower levels of oral language ability

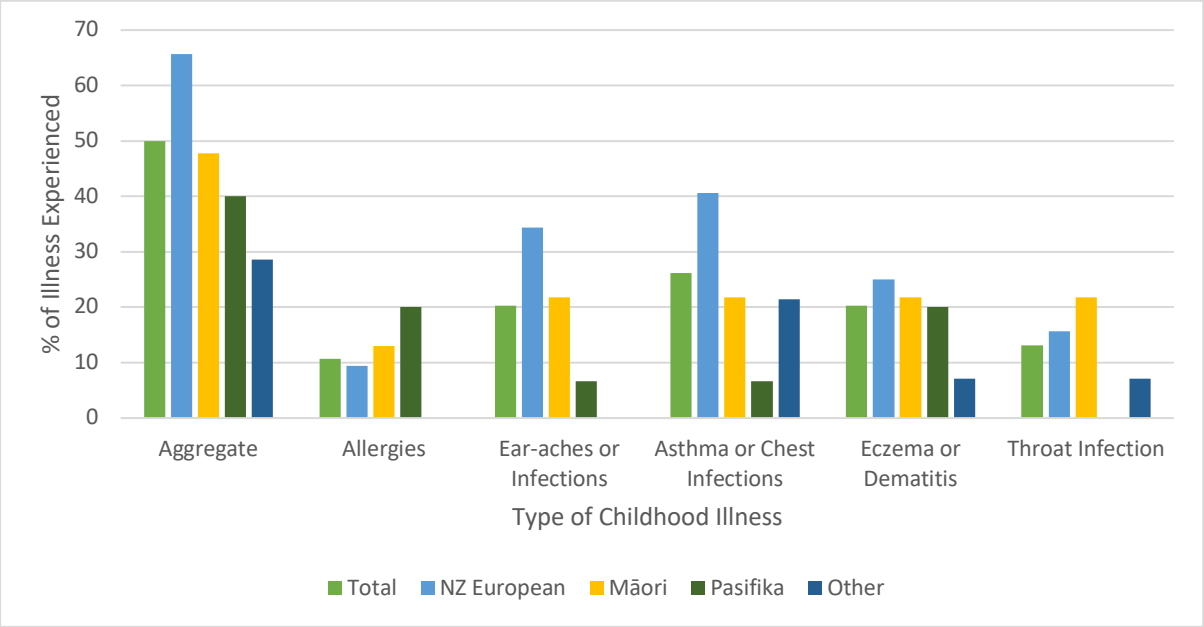
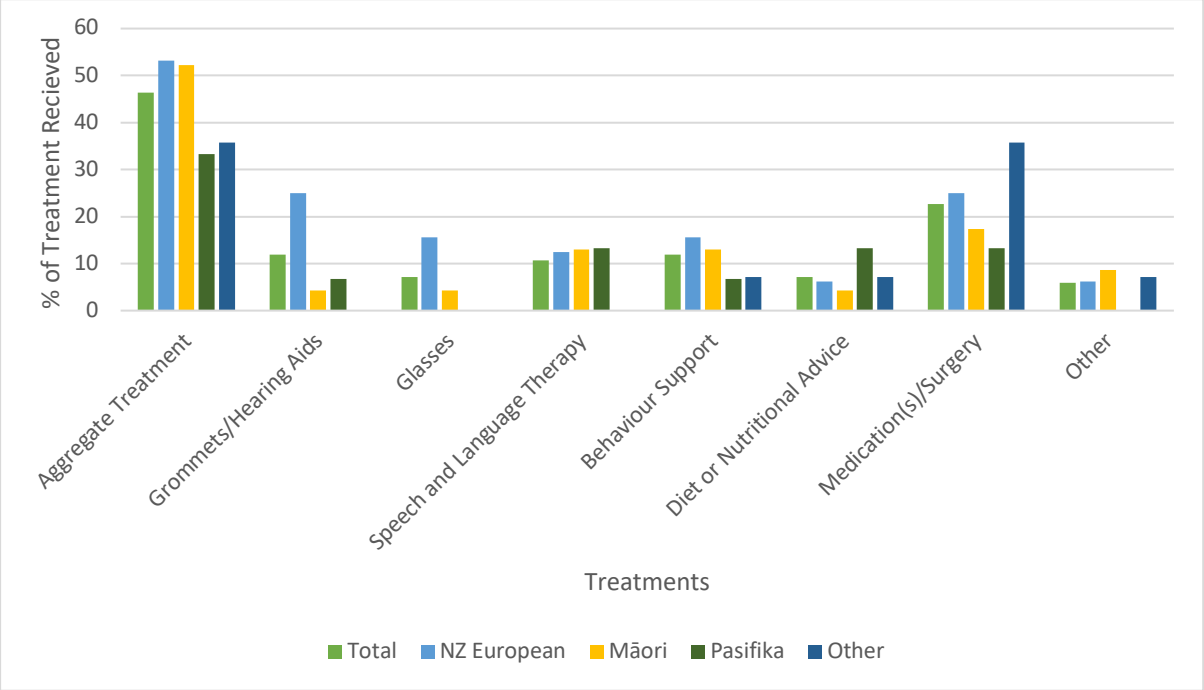


Figure 4.5

Treatment of new entrant children entered school with lower levels of oral language ability



The whānau questionnaire also asked parents to describe their child's health. None of the parents described their child's health as 'Poor', and 6 (7%) rated it as 'Fair'. The bulk of the answers described their child's health as 'Good' (n=42, 50%) or 'Excellent' (n=37, 44%). No significant differences were found in parent rating of overall health with parent health concerns (p=0.34), treatments received (p = 0.23), illness in the past 12 months (p = 0.08) or childhood illness (p = 0.29).

When matched to the areas of concern, there are mixed levels of health management and follow up care for different areas of concern. Parents who had concerns for their child's literacy, language and speech sought professional help 74% (n = 14) of the time. This support was mostly from educational staff (n = 8, 57%), followed by medical or health professionals (n = 3, 21%), both medical and health professionals (n = 2, 14%) and with one (7%) child having other professional help. Of those who were identified with speech difficulties by ABS researchers (n = 24, 32%), 14 (58%) had no professional support. Of those who were not identified as having a speech difficulty (n = 50, 68%), two children had received professional help for their speech difficulty (4%).

When comparing other concerns to treatment, 5 (50%) children received glasses due to their vision concerns, 9 (47%) children with behaviour concerns had some behaviour support, and 6 (67%) children given nutritional and dietary advice to address weight concerns. Children with other health issues were receiving treatment, around 50% of the time. Eight (10%) parents had concerns about their child's sleeping behaviour. Later in the questionnaire, parents were asked about their child's sleep habits, with 7 (9%) parents believing their child did not sleep well. One in four (n = 17) parents had concerns with their child's nightmares,

while 14 (17%) children had trouble going to sleep, 10 (12%) were waking at night, 5 (6%) were sleep-walking, and 4 (5%) were tired or sleepy during the day.

4.3.3. *Parent perceptions of sharing student health information*

When examining parents' views relating to sharing of children's health information data showed that the majority of participants (n = 51, 62%) believed that consent for student health information sharing should be "*given only when a request has been made for health data to be released*" while the remaining (n = 31, 38%) believed in opt-out consent process where consent should be "*automatically given as part of the school enrolment process*". Whānau recognised the value of teachers having health information with 71 (88%) participants agreeing that teacher awareness about a child's medical/health information is essential to the teaching and learning that happens at school. Despite the perceived value in teacher awareness, only 51 (61%) participants believed teachers should have access to health records. No significant differences were found when comparing participants who thought teachers should have access with those who did not in the number of health concerns, parent-report of general health, amount of treatment or illness in the past 12 months (see Table 4.3). Similarly, no significant differences were found between those participants who thought teacher awareness of health concerns were helpful to teaching with those who did not in the number of health concerns, parent-report of general health, amount of treatment or illness in the past 12 months (Table 4.3).

Qualitative explanation of binary answers

Over half of the participants (n = 49, 58%) who answered the teacher access question chose to provide reasoning or explanation to their answers, while 40 (49%) participants chose to provide explanations to their answers for the teacher awareness question. A total of 49 codes

Table 4.3

Comparing health profile to participant beliefs around sharing student health information with teachers

	Total		Teacher access question [a]					Teacher awareness question [b]				
			Yes		No		FET p-value	Yes		No		FET p-value
	n	%	n	%	n	%		n	%	n	%	
Parent-report of child's general health												
Excellent	37	44	20	56	16	44		28	82	6	18	
Good	42	49	25	60	17	41	0.12	38	93	3	7	0.35
Fair	6	7	6	100	0	0		5	83	1	17	
Poor	0	0	0	0	0	0		0	0	0	0	
Types of child health concerns												
Hearing	16	19	10	63	6	38	0.99	15	100	0	0	0.20
Vision	10	12	7	70	3	30	0.73	9	90	1	10	0.99
Speech	15	18	8	53	7	47	0.57	14	93	1	7	0.68
Behaviour	19	23	13	68	6	32	0.44	18	95	1	5	0.44
Learning	16	19	9	56	7	44	0.78	14	88	2	13	0.99
Movement or Mobility	1	1	1	100	0	0	0.99	1	100	0	0	0.99
Growth/Physical Development	2	2	1	50	1	50	0.99	1	50	1	50	0.23
Weight	9	11	6	67	3	33	0.99	8	89	1	11	0.99
Sleeping	8	10	4	50	4	50	0.71	6	75	2	25	0.26
Treatment received												
Have received treatment	39	47	24	62	15	39	0.99	37	95	2	5	0.09
Hearing treatment (grommets/hearing aids)	10	12	5	50	5	50	0.51	10	100	0	0	0.35
Vision treatment (glasses)	6	7	4	67	2	33	0.99	6	100	0	0	0.99

Speech	9	11	8	89	1	11	0.08	8	89	1	11	0.99
Behaviour Support	10	12	8	80	2	20	0.30	9	90	1	10	0.99
Physical Therapy Treatment	4	5	2	50	2	50	0.99	4	100	0	0	0.99
Diet Advice	6	7	5	83	1	17	0.40	6	100	0	0	0.99
Medication or Surgery	19	23	12	63	7	37	0.99	19	100	0	0	0.11
Common Childhood Illness (in the past 12-months)												
Allergies	9	11	5	56	4	44	0.99	8	89	1	11	0.99
Ear-aches or Ear Infections	17	20	9	53	8	47	0.58	14	82	3	8	0.43
Asthma or Chest Infections	22	27	9	41	13	59	0.04*	20	91	2	9	0.72
Eczema or Dermatitis	17	20	8	47	9	53	0.27	17	100	0	0	0.11
Throat Infections	11	13	7	64	4	36	0.99	9	90	1	10	0.99

[a] 2 missing cases (n=83)

[b] 4 missing cases (n=81)

were developed for answers to both the teacher access and teacher awareness question. Early thematic maps displayed the 33 codes developed for the teacher access question and the 16 codes developed from the teacher awareness question. When the themes were reviewed, three themes (*Safety at school*, *limits to sharing health information*, and *discussed with teachers and parent*s) from each question had sub-themes developed. Two candidate themes (*can assist teaching and learning* and *teacher more aware of the entire student*) in the teacher access and teacher awareness questions were combined, due to the teacher offering support to students in both candidate themes.

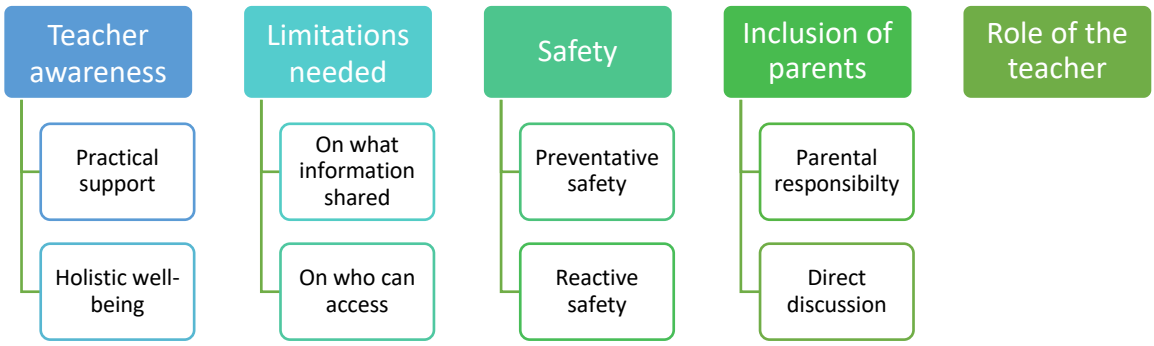
Miscellaneous codes were examined. The *Doctor-patient relationship* code moved to *limitations needed, personnel* sub-theme, the *private information* code moved to *limitations needed, information* sub-theme and the code *Teacher second parent* moved to the *not a teacher's role* theme. The two final codes, *uneasy if occurring already* and *medical industry overwhelmed,* were discarded from the analysis as they could not be analysed without extensive researcher input. When comparing the themes and sub-themes of the teacher access question to the themes and sub-themes of the teacher awareness question, four major themes overlapped. This overlap allowed for the analysis of both questions to be amalgamated creating a final thematic map of the five final themes (*school safety, teacher awareness, limitations needed, inclusion of parents,* and *role of the teacher*; see Appendix C.7 for the thematic mind map and Figure 4.6).

Theme One: School safety

In theme one, *school safety*, participants explained how sharing student health information could assist with student safety at school, and how teachers can prevent and react when they are more aware of their classroom's health information. Many participants saw sharing

Figure 4.6

Themes and sub-themes discovered in phase 1 thematic analysis



student health information as a way to facilitate safer school practices. *School safety* was split into two sub-themes, reactive and preventative safety.

Reactive safety

Participants discussed the need for teachers needing to be able to act or react when a health event occurs. The participants believed that if student health information were available, teachers would be able to act more appropriately (*"in case something happens in class…; if anything went wrong they [teachers] should know what to do; just in case something happens like an accident at school"*). The consideration of *reactive safety* focuses on individual safety, indicating that teachers of students with health concerns that could present at school must be aware to the teacher, especially if the concerns are *"life-threatening disabilities…"*.

Preventative safety

Participants discussed the need for teachers and schools to be aware of student health information for *preventative safety*. Participants believed that sharing student health information would help *"…make sure all children are healthy and not at risk of exposing*

others to anything" and minimise the spread of contagious illness. Further, *preventative safety* discusses the requirement for teacher and school awareness of immunisation history, which children may need to be further protected from disease and those who should be home, rather than at school in an outbreak. Another parent stated that *"My child is at school 6 hours a day, 5 days a week! I think it is extremely important for teachers to have access to their medical records"*. This comment acknowledges the importance of sharing information to their child's school due to a school's duty of care and the time they spend in school.

Theme Two: Teacher awareness

In the second theme, labelled *teacher awareness*, participants discussed that teachers are more able to provide support to their students with health concerns. *Teacher awareness* discusses that when teachers are aware of a student's health information, they can provide more personalised support to those who need it while understanding the health background of their class. Support was described by two subthemes, practical support for learning and holistic support. The first subtheme, *practical support*, discussed how, with student health information, teachers would be able to assist students with a health concern in a practical, learning-focussed manner. The second subtheme, *holistic welfare*, the teacher would be able to understand the child through a more holistic lens.

Practical support

Participants acknowledged the impact poor health could have on learning ("*...a child's state of overall health is going to have a strong impact on their ability to learn…"*). They discussed the potential when teachers are aware of health concerns facing their student "*…they can then offer any additional help a child may need"*, and adjust *"...*[how] *they need to be taught"*, and can *"...teach them to the abilities of their health"*. This practical support

focused on the child's ability to learn and how a teacher, knowing the student's health information, can adjust their teaching practice based on their classes' health profile. Once teachers are aware of the reasons for a student not meeting their full potential, they can tailor their classroom and teaching to more effectively overcome barriers to learning.

Holistic welfare

Holistic welfare discusses the more rounded support able to be given by teachers when they are made aware of health concerns. With awareness of students' background and health conditions, teachers will *"give a way of understanding any issues that come about because of their health or medical issues"*. Participants highlighted the need to understand where the child has come from as *"it gives an idea to the teachers of the level of care the child needs"* and *"...may explain learning difficulties"*. Participants indicated that students might feel more supported and understood if this health information was shared. With access to student health information, teachers and schools may be better equipped to provide more efficient practical and holistic support to students and their whānau.

Theme Three: Limitations needed

The third theme, titled *limitations needed*, articulated concerns around access to health information. These concerns discussed two subthemes, the first considered limitations to who should be able to access students' health information, and the second considering limitations to what health information should be shared. Many participants did not support unlimited access and highlighted necessary limits on what and how information is shared for participant agreement. The *limitations needed* theme also emphasises the challenges in binary yes/no answers, further justifying the need for more in-depth, meaningful conversation into whether health information sharing with teachers is a beneficial idea.

Limitations on personnel access

Participants highlighted the need to consider who should handle students' health information. Participants discussed the *Dr-patient relationship,* and how health information "*should be kept between doctor and family*" with sharing health information with teachers being "…*a breach of doctor/patient confidentiality"*. A participant, who answered no to teachers having access to student health information highlighted that *"... a health nurse maybe"* could access the information. This statement emphasises whether professionals such as teachers, who do not work in the health sector, should be aware of health information that may be affecting the students' school performance and greater holistic well-being. The statement also asks the question of why health professionals are better equipped to handle this information when teachers are often aware of sensitive information. Another participant, who thought teachers should be able to access student health information, thought *"senior teachers anyway"* opening discussion to whether all teachers can be trusted and held to the same accountability when handling this information.

Limitations on the types of information accessed

Participants also questioned the types of information shared and why the information is being shared. Many participants stated that they support teachers accessing information if it was learning specific (*"only the ones that would impact on learning and teaching…)* or if it was impacting other students (*"only the ... health records which may affect others"*). Participants who answer no to the teacher access or teacher awareness questions gave similar explanations to participants who answer yes. This similarity indicates that participants saw value in quantifying their answers with a statement on what information was acceptable to share

(*"only if it interferes with learning and behaviour"*, and *"no unless the medical health of a child hinders their learning ability"*).

Theme Four: Inclusion of parents

Theme four, identified as *inclusion of parents*, portrays the role parents have in keeping their child's health information secure as well as their right as a parent to be in control of this information. Participants expressed their concerns about parents not being involved in the accessing of health information and how teachers can easily discuss their concerns about a student with the student's parent. Two sub-themes*, parental responsibility*, where participants discussed what was shared was up to the parents, and *direct discussion*, where participants highlighted the need for parents to be well informed, their consent given and teachers to be able to discuss any concerns with parents directly.

Parental responsibility

Parental responsibility discusses the need for parents to be in primary control of any information relevant to their child. Participants believed that parents have a responsibility to discuss any health concerns with the teacher (*"parents could let the teacher know if there are any concerns"*). Participants also saw the value of sharing student health information, however, believed it was the parents' responsibility to share the information *"parents/carers should share what is relevant"*. As with the *limitations needed* theme, the binary approach of the question does little justice considering the complexity of sharing potentially sensitive information. The role of parents in sharing student health information is a vital part to consider when discussing a potential health information sharing system and heavily links back to the previous theme, *limitations needed*. *Parental responsibility* starts questioning the

role of parents and teachers while discussing the required limitations on what information is shared and what school staff could access that information.

Direct discussion

The majority of participants whose statements were put into the *direct discussion* theme believe the teacher should not have access to their students' health information (n=8, 89%). These participants believed that teachers should ask parents if any health concerns may be impacting their school lives ("*anything wanting to know should be discussed directly with parents*"). *Direct discussion* centres around the principle of control, with parents wanting to be aware of what teachers know about their child's health and how that information is being used. By talking directly to a teacher or school staff member, there is additional personalisation, where the sharing of health information is personally communicated and linked to a child. That information will be linked to a child through discussion, rather than to a name on a computer system.

Theme Five: Role of the teacher

The final theme, the *role of the teacher*, illustrates how beliefs around the role of the teacher intertwines with many other themes. It discusses how participants have conflicting views about the role of a teacher and how these views impact their views on whether a teacher should have access to a student's health information. Participants highlighted the idea of health information only being privileged to health professionals (*"they're not doctors")* and link to the consideration on who should be able to access health information discussed in theme three. Conversely, other participants believed *"a teacher is the second parent of the student"*. Many participants expected teachers to be able to act in emergencies, take on the

role of caregiver, and provide SEMH support ("*if the child is not really well physically or emotionally, they know how to support them*").

Summary of themes

Findings from this thematic analysis identified five themes. *School safety, teacher awareness, inclusion of parents,* and *limitations needed* were well supported by the data, with sub-themes developed to highlight the different categorisation of these themes in order to show a more rounded interpretation of the data. While these themes stand alone, they also are entangled with each other and combine to form a complex perception around sharing student health information with teachers. The *role of the teacher* theme was entangled with the other themes, particularly *school safety* and *teacher awareness*.

4.4. Discussion

This study was able to identify and ask parents of early learners with lower levels of oral language ability a range of questions relating to their child's health. It also explored the perceptions of parents on sharing student health information with teachers and schools.

4.4.1. *The health of new entrant students with low oral language levels*

This study found that over half of children with low oral language ability had one or more health concerns It also found a higher percentage of children who have asthma (23%) and eczema (20%) than data collected by the Ministry of Health (2019) on children aged 5-9 years of age (14% and 17%, respectively). These common health concerns identified are essential factors for academic achievement, with the impact of asthma and eczema discussed in chapter two. Schluter et al. (2020) found that parent concern for their 4-year old child's

behaviour, development, and speech and language skills were closely associated with being identified as needing literacy intervention in their first few years at school. This association may provide reasoning for the high levels of parental concern in this study.

One of the main reasons for sharing health information with teachers is the ability for teachers to manage illness or health and well-being concerns in the classroom (Wodrich, 2005). This questionnaire found that support from education staff such as teachers is highly sought after by parents who expressed concerns with a child's literacy, language and speech. This finding emphasises the need for continual specialist education professionals, such as speech-language therapists (SLTs). They are relied on heavily (almost 66% of the time) when concerns of this nature arise and supports research by Snow (2009) to start integrating speech language therapy (SLT) intervention with health intervention. Parents' ability to correctly identify speech concerns was found to be low and is supported by findings by Schluter et al. (2020) who found that parental concerns with "…*behaviour, development, speech and language, or fine and gross motor skills at age 4 years was also associated with their child receiving a literacy intervention in their first few years at school*" (page e72). If parental concerns are not a good indicator of actual speech concerns, and parents remain unaware of their child's need for speech intervention, many children may be excluded from interventions that could significantly improve their literacy outcomes (McAllister et al., 2011).

This finding also acknowledges the importance of these professionals providing support for children who are struggling to keep up with their peers. Without support form education or health professionals, children with SLC may struggle to match their peers and continue to have significantly lower academic success than their peers (McLeod et al., 2019). The two students who had received past professional support for SLT may have led to their

impairment being resolved (and thus their answer that they did not have a speech difficulty at the time of data collection). This finding may indicate the positive outcome professional support had had for these children.

This study did not investigate the reasons why 45 (54%) children with one or more parent-identified health concerns did not receive treatment. Barriers to access, such as logistical or financial barriers can often stop individuals from seeking treatment and maybe some of the reasoning behind over half of children not receiving treatment (Lazar & Davenport, 2018). Many children who experience mild-moderate speech difficulty do not qualify for funded SLT or other government-funded treatments (McAllister et al., 2011). If treatment for health concerns is not sought or attained (due to not meeting the criteria for treatment), poor management of health can have significant effects on daily functioning and long-term outcomes according to Palloni and Milesi (2006). These effects may be exacerbated further if the health concern impacts new entrant children learning vital literacy skills (Gillon et al., 2019)

The effects of sleep, obesity, SLC and mental well-being on academic achievement and life outcomes is well documented (Carroll & Hurry, 2018; McLeod et al., 2019; Taras & Potts-Datema, 2005a, 2005b). With 55% (n = 46) of participants in this study having concerns with their child's health, there is a need to address these concerns, and a real potential for data sharing to facilitate the management of health within the education system, alongside the health system. Those children experiencing poor sleep and obesity are more likely to experience increased absences (Reynolds et al., 2018), negative emotions and shyness (Berger et al., 2018) and psychological consequences from obesity stigmatisation (Asirvatham et al., 2019). This multi-sector approach recognises the value of health in

education and the impact that health can have an academic achievement and literacy development. The findings in this health profile justify further investigation into what a health information sharing system would look like, discussion of the risks and solutions, and what the public – and in particular parents and teachers – think about a student health information sharing system.

It is also essential to consider the consistency between answers due to the parental report nature of the questionnaire. High levels of parent-rated health were reported in this study (93%) and the Ministry of Health New Zealand Health Survey (97.9%), despite the prevalence of health concerns in both studies (Ministry of Health, 2019). By comparing answers given to different questions, we were able to identify some inconsistencies, particularly in the rating of their child's general health. These inconsistencies demonstrated the potential of parental report bias. By asking specific questions, such as whether the child had experienced any common childhood illnesses, the study was able to better establish an understanding of the health of these children than we would have if we had simply asked, "*Which word best describes the health of your tamaiti/child/tama*?".

4.4.2. *The complex nature of health information sharing*

The second aim of this chapter was to discuss with parents of children entering school with low oral language ability, their perceptions about sharing student health information with educators. The majority of participants believed that consent for health information should be requested separately from enrolment determining for an opt-in style of consent, emphasising the need for discussion of the consent process when sharing student health information. According to Johnson et al. (2002), this opt-in strategy discussed by participants may be closer to their actual preferences for consent when asked about sharing health information.

Consent was also discussed throughout the thematic analysis, complementing the *inclusion of parents'* theme, which highlight participants beliefs about parents being involved in consent.

Participants who believed that teacher awareness and school safety were benefits arising from sharing student health information also believed teachers should have access to student health information. They also thought that teacher awareness of student health information was essential to the teaching and learning that happens at school. Acknowledging the benefits of sharing health information with educators is essential as there must be value in sharing information according to the Privacy Act 1993 ("Privacy Act 1993,") and is one of the core values set out by the New Zealand Data Futures Forum (2017).

Those who thought teachers should not have access to student health information discussed the inclusion of parents (93%) and how limitations were needed (38%); while the majority of those who answered no to the teacher awareness question explained their answer due to limitations needed (60%). Further research needs to consider which staff members should have access and what information should be shared regularly. Should all teachers be allowed, or only teachers involved with the student, i.e. their classroom teacher? What about health staff, senior management, admin staff (who are often the people handling the information), and public health nurses who are associated but not employed by the school?

Participants discussed health concerns such as seizures or allergies that are apparent for parents to make teachers and schools aware of, as its potential effect on basic school safety is evident. However, illnesses with more "silent" reactions may not be shared as willingly, especially if parents don't acknowledge the impact the health concern could have in the classroom (Wodrich, 2005). An example may be a child with T1DM, whose blood sugar

level is dropping (Cunningham & Wodrich, 2012). As a result, they struggle to concentrate and not be able to learn at their full capacity. With this in mind, a greater understanding of the muted impact some health concerns have on learning ability may have influenced participant perceptions towards sharing a broader range of health information. Participants highlighted limitations to what information should be shared, making delineations between learning and health issues. These views open up to further questioning, such as, what is a health issue and what is a learning issue? Do parents understand the ways health concerns can impact learning? Do health and learning issues overlap? Moreover, if they don't overlap, is it acceptable to share that information?

Findings from this sample highlighted the conflict between the benefits of teachers being aware of student health information and the cautiousness required due to the potential risks. While almost 90% of parents believed that teacher awareness of student health information was essential to teaching and learning, only 61% thought teachers should have access to student health records. These findings were to be expected and match previous research where concerns for privacy and security weighed heavily on participants willingness to share sensitive health information (Damschroder et al., 2007). The thematic analysis allowed a more in-depth analysis of this discrepancy. Participants who believed teacher awareness of student health concerns would help teaching and learning but did not think teachers should access to this health information gave explanations that discussed the *Inclusion of Parents* and *Limitations Needed* themes. For example, a participant answered "*... I don't believe the teacher should have access to any child's medical records. Any information would be at the parent or caregiver's discretion*" to the teacher access question, but thought teachers should be aware of a student health concern because "*...it is important for the teacher to be advised and made aware of any health or medical issue that may affect the child's learning...*". These

beliefs acknowledge the benefits of sharing student health information with teachers for learning purposes, but highlights that it should be left to the parent to share this information rather than the information being openly accessible to the teacher. These discrepancies emphasized that dichotomous yes and no answers to the questions asked were insufficient to adequately explain participants' opinions with many participants justifying their answers with "only if…" or "but…". The binary approach forced participants to answer the question, but it is essential to allow participants the opportunity to provide further explanation.

The final theme, the *role of the teacher*, uncovered that parents differ in their expectations of teachers in terms of sharing health information. Participants believed teachers should not have access to student health information as *"they are teachers – not doctors*". These views emphasized the belief that health information should only be accessible to doctors and stay within the health sector. However, other participants felt that teachers are "*... the second parent of the student*", highlighting the teacher role being more than a purely educational (Lanier, 1997). The juxtaposition of these statements points out the differing parental beliefs of the role and expectations of teachers. While not directly stated, expectations of teachers are a topic present in many of the themes found in the analysis. Expectations of teachers to know what to do in the case of a health issue, to understand the student and their health background, to adjust their teaching based on health concerns, to provide the support that improves academic outcomes, and discuss health concerns with parents all discuss what parents believe the role of the teacher is, without expressly asking them the question. In these examples, teachers are expected to play multiple roles in the classroom, which begs the question, what is the role of a teacher and school in today's education system?

Four of the five themes match the four principles developed by the NZDFF (New Zealand Data Futures Forum, 2017). *Limitations needed* to discuss the need for only certain personnel and specific information to be shared, consistent with the *Control* principle where individuals should be able to determine what information is shared and how that information is used. This principle also highlighted the importance of informed consent, again consistent with findings in this study that stated a request must be made to the parent, separate to enrolment (New Zealand Data Futures Forum, 2017). The *inclusion of parents'* theme, which highlighted the importance of working with parents in their child's health is managed can be linked with the *Inclusion* principle and also the *Trust* principle. These principles, along with findings from this research, are further supported by recognising the importance of building trusting whānau-teacher relationships (American Federation of Teachers, 2007).

Including the NZDFF's *trust* and *inclusion* principles will help parents see the benefit from information sharing, increase their understanding of how their child's health may be impacting learning, and build trust in the process that information is shared and managed(New Zealand Data Futures Forum, 2017). The *teacher awareness* and *school safety* themes complimented the Value principle, where sharing information must be a valuable and beneficial endeavour and must have valid reasons to share information according to the Privacy Act 1993 ("Privacy Act 1993,"). By sharing student health information, students benefit as their learning, and holistic welfare is better supported (due to a better understanding of student health and background). At the same time, teachers are better able to support and create a better informed, safe school environment.

4.4.3. *Limitations*

The results of this study rely heavily on parental report, and thus, the research must consider the limitations of parental report when discussing the findings. For this research, parents may not have given an accurate report of their child's health due to stigma or bias (Bentley et al., 2016; Corrigan & Rao, 2012; Liebschutz et al., 2008; Rose et al., 2011). Parents often over or under-estimate their child's health leading to potentially biased results (Elgar et al., 2005; Levi & Drotar, 1999; Rosenman et al., 2011; Sawyer et al., 1999). In contrast, Gruber et al. (2019) discussed that parents are a valid source of some information such as sleep concerns. These findings thus should be considered as being potentially limited due to limitations associated with parental report.

Limitations also surrounded the questionnaire. The design of the full whānau questionnaire bought together research questions from multiple researchers. As a result, not all questions were tested for external validity and reliability, a limitation in many health and social science research (Bolarinwa, 2015). Future research needs to consider the validity of questions, utilising questions from commonly used, validated questions, such as the SDQ.

Another limitation of this research centres on its ability to be generalised to the general public. With a modest sample size of children entering school with lower oral language ability and use of convenience sampling in eastern Christchurch, the research is likely to have limited generalisability (Etikan et al., 2016). In particular, all seven schools were located in two lower socioeconomic communities, a factor that has been linked to poorer health outcomes and school success (Hair et al., 2015; Pickett & Pearl, 2001). The study was of modest sample size, which limits the ability to make reliable conclusions (Hackshaw, 2008). However, the decision to utilise convenience sampling was due to its ability to pilot research,

with the findings from this study to acknowledge areas for more detailed research and to be used in further studies within this thesis.

Issues also exist in the interpretation of language in the questionnaire. Due to the relatively new idea of sharing "health information", participants may have been unsure of the meaning of "health information" and what it encompasses. The definition of health information in the information sharing context needs research into itself, particularly around what information it encompasses. While chapter five and six begin the process of looking at what health information is shared, it is essential, particularly in the early development of student health information, to not start too narrowly in case other health conditions were to be of interest.

4.4.4. *Implications and next steps*

This study has identified that there is a high prevalence of parent-identified health concerns in our sample of new entrant students who entered school with lower levels of oral language ability. This finding may indicate an association between poor health and low oral language achievement in the early years of schooling, however further research is necessary to consider other contributing variables to low oral language development. The impact of health on education can exacerbate inequalities, particularly when considering the potential long-term effects of poor health and low educational achievement (Case et al., 2005; Hair et al., 2015; Thies, 1999). At age 5-years, ethnic, gender, and SES disparities in successful literacy learning are apparent (Schluter et al., 2020) and by continuing with the current status quo, these disparities are likely to persist into adolescence and adulthood. For teachers to improve life outcomes for students, they need to be fully aware of their students' health concerns and how to manage them effectively in the school environment (Cunningham & Wodrich, 2006;

Thies, 1999). By supporting these students more effectively, literacy levels may improve and alter the potential of academic achievement in childhood – an achievement that can have ongoing implications for earning potential, health outcomes and well-being from childhood through to adulthood.

This phase of the research concluded the need for continued discussion and investigations of parents' perception of health sharing. The research established that over half of participants were open to sharing health information, and further research must lay the foundations in establishing a new system and more in-depth analysis undertaken to establish whether student health information sharing is beneficial. The explanation given by participants, and thematic analysis that followed, began the investigation into parent perceptions. The next chapter builds on the parent perception findings, attempts to answer the questions posed during this study and broadens the participants to include the potential users of this health information, teachers and education professionals. The findings reported here helped form the questionnaire used in the next chapter by developing questions focused on the themes that were found and answering the questions that were posed.

Chapter Five Phase 2: Teachers' Perceptions

The previous chapter discussed the impact health could have on school success and the prevalence of health concerns within several schools in Christchurch. This impact demonstrates the need to look outside the current way in which health is managed and consider ways to incorporate schools into effective health management. The creation of a digital student health information sharing system (DSHISS) for teachers has the potential to help schools better understand their students and manage student health concerns. It is essential then, to also explore the perceptions of kaiako (teachers) and other school staff on a DSHISS. Kaiako and education staff can give real examples of how the system could be utilised, what it could look like and how to work with the community for successful implementation. By including teachers, the system gains a unique perspective that adds significant value in justifying the need to share student health information with schools.

This chapter aims to build on the findings from phase 1, asking teachers and other school staff their perceptions of a DSHISS and has two parts, phase 2A (which derives its data from a questionnaire) and 2B (which derives its data from focus groups). In phase 2A, participants from three different schools were asked to complete a short questionnaire that was developed from answers in phase 1 and includes both closed and open-ended questions. Closed-ended questions were subject to statistical analysis, while open-ended questions were subject to descriptive thematic analysis. A semi-structured interview schedule developed from the questionnaire findings. For Phase 2B, participants were asked to take part in a focus group. Participants had the opportunity to expand on any topic, discuss disagreements and come up with solutions to concerns. This approach allowed for an in-depth discussion that enabled

participants to discuss their beliefs within their worldviews, using their own experiences to support their views.

5.1. Aims

This chapter aims to build on phase one findings and include teachers in the discussion about a DSHISS. Phase 2 expands on the questionnaire by discussing teacher thoughts on sharing student health information. This phase deepens the analysis done in phase 1 and utilises open discussion to allow participants to analyse their own and others' views.

5.2. Phase 2A – Kaiako Questionnaire

5.2.1. *Method*

Participants

To be eligible for the research, participants from three participating schools around Canterbury and were required to be:

a) teachers of children in school years 0-2
b) in management positions that dealt directly with staff of children in year 0-2, or
c) support staff (teacher aides or pastoral care) that interacted with children in year 0-2.

Participants who met criteria A were categorised as Kaiako. Due to the small number of participants eligible, those who met criteria B or C were amalgamated and categorised as Other Educational Staff.

Questionnaire Development

The kaiako questionnaire was developed by the researcher as there was no pre-established measure to discover perceptions toward sharing student health information. It utilised

questions and findings described in chapter 4 (phase 1). Several considerations were made in the development of this survey to ensure higher response rates and participant enjoyment. One concern was the length of the questionnaire. Edwards et al. (2002) found that shorter questions had a higher response rate than longer questionnaires. As such, it was a priority to ensure that these questionnaires were short and concise, allowing participants to complete without a significant time burden while ensuring detail was not compromised. Instead of leaving answers open-ended, most questions allowed for tick box answers (developed from themes uncovered in phase 1), while still leaving an '*Other'* option for participants to expand on their views. The wording was another careful consideration made in the questionnaire development. It was essential to ensure minimal jargon, complex, or discriminating language was used. The inclusion of te reo Māori and use of examples alongside any medical terminology created a more straightforward and inclusive questionnaire for participants of any background. A final consideration was given to the flow of the questionnaire.

The final kaiako questionnaire consisted of 13 main questions and six demographic questions as well as the attached consent form and information sheet (see Appendix D.1). Three questions were repeated, word for word, from the whānau questionnaire for comparative purposes, and gave participants the opportunity to choose from two options and explain their choice (teacher's questionnaire Q1, Q2 and Q6; parent questionnaire Q3, Q4 and Q7).

Two questions discussed the limitation needed theme developed in chapter four and asked participants their thoughts about who should access student health information, what health information would participants be comfortable accessing and what types of health information would assist their ability to teach. Themes from phase 1 (school safety, teacher

awareness and inclusion of parents) were included in questions that discussed the role of the school, teacher and parent.

Participants were asked about the benefits and concerns of sharing student health information with educators with several options given, as well as an option to add other comments. The remaining questions asked participants to rate their agreement that "*the benefits and value of sharing health information outweigh the risks"* on a 5-point Likert scale, and asked participants if they had any final comments. Demographic questions asked for gender, year born and ethnic group, as well as the participant's role at school (e.g. kaiako, senior management), which school they work at and the number of years teaching.

Two teachers outside of the target group piloted the questionnaire to ensure they were easy to follow. Both found the questionnaire easy to follow, thought-provoking and taking just under 10 minutes to complete. No alterations were recommended or made. The digital version of the questionnaire was tested by one member of the supervisory team, with only a couple of grammatical and display changes made.

Procedure

Headteachers from three participating schools (discussed in section 3.5) were asked to email the questionnaires out to eligible participants. The original invite included the offer for hard copies if preferred and for the researcher to come into schools and discuss the questionnaire face-to-face. One of the schools accepted an invitation for the researcher to go in with morning tea and discuss the questionnaire with eligible staff. Follow up of the questionnaires included individual emails to each staff member by the researcher, reiterating the topic and their voluntary participation, and offering hard copies.

Data Analysis

Various quantitative analyses were used in phase 2A (with greater detail found in section 3.4). An ANOVA was employed to compare the age of participants across schools. FET measured differences in questionnaire answers between schools and the role of the participants (as kaiako or support staff) and analysed differences between schools or by role for the Likert scale. Further, Cohen's kappa was used to measure the level of agreement between information that would assist a teacher's ability to teach and what information teachers would be comfortable accessing.

As discussed in chapter 3.4, phase 2A had a shortened version of a thematic analysis undertaken. The researcher went through these comments and noted that the majority of comments were able to be placed into themes discussed in chapter four. Those comments that did not fit into these pre-establish themes were highlighted and considered for discussion in the focus groups in phase 2B. For inter-rater reliability, another researcher looked over the themes. This researcher flagged one comment that she thought was better suited to another theme. After discussion with the primary researcher, the researchers agreed to place this comment into a different but more appropriate theme.

5.2.2. *Findings*

Response Rates

A total of 43 education staff, 21 kaiako and 22 other education staff were eligible to complete the questionnaire, with a total response rate of approximately 60%. The majority of kaiako

(90%) completed the questionnaire (19 questionnaires completed, seven from School A and six questionnaires from School B and C), while 32% of other education staff participated.

Demographics

Participants were made up of mostly NZ European females and ranged from new graduates through to retirement age (see Table 5.1). No significant differences in key demographics were found between schools ($p > 0.05$); see Table 5.1.

Table 5.1

Demographic information of education staff participants

Characteristic	School						Total		p-value
	A		B		C				
	n	%	n	%	n	%	n	%	
Gender									
Male	3	23	1	17	0	0	4	15	0.65
Female	10	77	5	83	7	100	22	85	
Ethnicity [a]									
NZ European	9	69	5	83	7	100	21	80	0.82
Māori	4	31	0	0	1	14	5	19	
Pasifika	1	8	0	0	0	0	1	4	
Asian	1	8	0	0	0	0	1	4	
Other	0	0	1	17	0	0	1	4	
Role									
Kaiako	7	54	6	100	6	86	19	73	0.11
Other Education Staff	6	46	0	0	1	14	7	27	

[a] ethnicity includes every option ticked, thus some children had multiple ethnicities

Teacher access, teacher awareness and consent

The majority of participants were positive towards the idea of sharing student health information with teachers. The vast majority of participants (88%) recognised health information as beneficial for teachers to be aware of, while 85% of participants believed

teachers should have access to their students' health information. There were no significant differences for the teacher access and teacher awareness questions between the two different participant roles at school and by school, respectively. This finding indicates that participant roles, nor the school they worked, had impacted their beliefs for both questions.

When asked about consent, 17 (65%) participants were in favour of automatic consent given with enrolment. No significant differences were discovered when comparing school answers to the consent question ($p = 0.65$). However, a significant difference was found when comparing kaiako answers with other education professional answers ($p = 0.03$). The per cent of kaiako who thought consent should be given automatically (79%) was significantly higher than that of the other education professionals (29%, $p = 0.03$). This finding suggests that the role a participant has at school, not the school itself, may impact how the participant thinks about giving consent.

What health information should be shared?

Hearing and Vision and Life-Threatening Illnesses was information that all 19 teachers and six (86%) other education professionals believed would assist teaching. Mental health ($n = 18$, 95% of teachers; $n = 5$, 71% of other education professionals) followed by ongoing medical conditions ($n = 17$, 89% of teachers; $n = 4$, 57% of other education professionals), and recurring illness ($n=16$, 84% of teachers; $n = 4$, 57% of other education professionals) were the next types of information that participants believed would assist teaching. Five (19%) participants, all of whom were teachers, believed that all medical records would assist teaching. The research also looked to see whether any of the results were significantly different by school (FET, $p = 0.54$) or by the participants' role in school (FET, $p = 0.28$). No

significant differences were found. When asked what information participants would feel comfortable sharing, answers shifted (see Table 5.2).

Who should be able to access student health information?

Over half of the participants thought principals (65%), senior management (65%), the student's classroom teacher (62%) and health staff (58%) should have access to student health information. Significant differences emerged between schools (FET, $p = 0.02$) and between roles (FET, $p = 0.03$) when asking about whether principals should have access to health information. Teachers (79%) and participants from School B (100%) and C (86%) believed principals should have access to health information more than participants consider other staff (29%) and from School A (39%; see Table 5.2).

Parent roles

Participants considered the roles of parents in sharing student health information. None of the 26 participants thought a child's health information should be kept between whānau and the doctor. This finding indicates that some health information should be shared with people outside the doctor-patient/whānau relationship. Over three-quarters of participants believed that one of the roles of parents was to provide teachers with relevant health information (n = 20, 77%), while 18 (69%) participants believed that the role of parent was to allow access to health information that concerns learning. These roles considered the theme from chapter four on limitations of the types of information that is shared, indicating the need to discuss what is relevant information. Seventeen (65%) participants believed parents had a role in consenting to access to health information (see Table 5.3).

Table 5.2

Findings of kaiako questionnaire by question

Questions asked and answers given	Overall		School						FET, p-value	Role				FET, p-value
			A		B		C			Kaiako		Other Staff		
	n	%	n	%	n	%	n	%		n	%	n	%	
Do you think that a teacher should have access to a child's medical/health records? [a]	22	85	10	77	6	100	6	86	0.78	15	79	5	71	0.29
Do you think that teacher awareness about a child's medical/health information is important to the teaching and learning that happens at school? [a]	23	88	10	77	6	100	7	100	0.40	18	95	5	71	0.17
Consent to student health information should be:														
Automatically given	17	65	8	62	5	83	4	57	0.65	15	79	2	29	0.03
Given with request	9	35	5	39	1	17	3	43		4	21	5	71	
What information would be helpful for teachers? [a]														
Hearing and Vision	25	96	12	92	6	100	7	100	0.99	19	100	6	86	0.27
Life threatening illness	25	96	12	92	6	100	7	100	0.99	19	100	6	86	0.27
Ongoing or chronic illness	21	81	9	69	5	83	7	100	0.38	17	89	4	57	0.10
Immunisations	13	50	6	46	3	50	4	57	0.99	11	58	2	29	0.38
Mental Health	23	88	11	86	6	100	6	86	0.99	18	95	5	71	0.17
Recurring Illness	20	77	9	69	5	83	6	86	0.84	16	84	4	57	0.29
Oral Health	12	46	6	46	1	17	5	71	0.18	10	53	2	29	0.39
All medical information	5	19	3	23	0	0	2	29	0.54	5	26	0	0	0.28

What information should you be comfortable accessing? [a]														
Hearing and Vision	25	96	12	92	6	100	7	100	0.99	18	95	7	100	0.99
Life threatening illness	25	96	12	92	6	100	7	100	0.99	18	95	7	100	0.99
Ongoing or chronic illness	21	81	9	69	6	100	6	86	0.45	16	84	5	71	0.41
Immunisations	14	54	5	39	4	67	5	71	0.40	11	58	3	43	0.40
Mental Health	19	73	11	85	3	50	5	71	0.32	13	68	6	86	0.37
Recurring Illness	21	81	10	77	5	83	6	86	0.99	15	79	6	86	0.99
Oral Health	15	58	7	54	2	33	6	86	0.20	12	63	3	43	0.31
All medical information	2	8	1	8	0	0	1	14	0.99	2	11	0	0	0.99
Who should have access to student health information? [a]														
Classroom Teacher	16	62	6	67	4	67	6	86	0.22	13	68	3	43	0.37
Health Staff	15	58	8	62	4	57	3	50	0.99	11	58	4	57	0.99
Principal	17	65	5	39	6	100	6	86	0.02	15	79	2	29	0.03
Senior Management Staff	17	65	6	46	5	83	6	86	0.17	14	74	3	43	0.19
Support Staff	8	31	4	31	1	17	3	43	0.75	6	32	2	29	0.99
Teachers in Year Group	6	23	1	8	3	50	2	29	0.08	6	32	0	0	0.16
None	1	4	0	0	0	0	1	14	0.50	1	5	0	0	0.99

[a] Reflects the number and percentage answering “yes” to this question.

The answer to question seven, *to give consent for access to health information*, was significantly different in proportion between schools (FET, p = 0.02). On further analysis, this difference was found within kaiako from different schools (FET, p = 0.01). This analysis found that kaiako from School B and C (n = 6, 100% and n = 6, 87% respectively) viewed consenting to health information as a parent's role proportionately more than kaiako from School A (n = 2, 29%). Significantly less participants from School A (n = 7, 58%) believed parents had a role *"to ensure teachers have relevant health information regarding students with health concerns"* compared to School B and C (n = 6, 100%; n = 7, 100% respectively, FET, p = 0.03).

Teacher Roles

The roles of the teacher were also asked (see Table 5.3), with 88% (n = 23) believing teachers need to understand students' health backgrounds and provide emotional and social support when needed. One of the answers concerned the *reactive safety* theme from chapter four, with 21 (81%) believing teachers need to know how to act if a medical incident was to occur. Over three quarters felt that teachers need to adjust teaching according to the child's health background (77%, n = 20). At the same time, two-thirds agreed that a teacher's role was to ensure limitations were in place for whom they share information with (69%, n = 18). More participants who identified as kaiako thought "*a teacher's role is to be fully aware of any student health concerns*" (n = 15, 80%) compared to other education staff (n = 2, 29%; FET, p = 0.03). No differences were found between schools (FET, p = 0.08).

Table 5.3

The role of parents, teachers and schools in managing student health

	Overall		School						FET, p-value	Role				FET, p-value
			A		B		C			Kaiako		Other Staff		
	n	%	n	%	n	%	n	%		n	%	n	%	
Parent role [a]														
To ensure teachers have relevant health information regarding students with health concerns	20	77	7	54	6	100	7	100	0.03	16	84	4	57	0.29
To allow teachers access to health information that could concern the child's learning	18	69	8	62	5	83	5	71	0.86	14	74	4	57	0.64
To provide teachers with relevant health information	20	77	8	62	6	100	6	86	0.20	16	84	4	57	0.29
To ensure their child does not put other children at school at risk of infectious illness	15	58	5	39	5	83	5	71	0.17	12	63	3	43	0.41
To allow teachers access to health information that could concern the safety of others at school	15	58	5	39	5	83	5	71	0.17	12	63	3	43	0.41
To give consent for access to health information	17	65	5	39	6	100	7	100	0.02	14	74	3	43	0.19
To limit who can access their child's health information	6	23	2	15	3	50	1	14	0.34	5	26	1	14	0.99
To keep a child's health information between the whānau and the doctor	0	0	0	0	0	0	0	0	-	0	0	0	0	-
Teacher role [a]														
To know how to act in a medical incident	21	81	9	669	6	100	6	86	0.45	16	84	5	71	0.59

To ensure a students' private information is only shared with individuals on a need to know basis	18	69	9	69	5	83	4	56	0.75	14	74	4	57	0.64
To provide emotional and social support when required	23	89	11	85	6	100	6	86	0.99	17	89	6	86	0.99
To understand students' health backgrounds	23	89	10	77	6	100	7	100	0.40	18	95	5	71	0.17
To adjust teaching according to students' health background	20	77	8	62	5	83	7	100	0.16	16	84	4	57	0.29
To be fully aware of any student health concerns	17	65	6	46	6	100	5	71	0.08	15	79	2	29	0.03
To act on the parents' behalf when necessary	13	50	4	31	3	50	6	86	0.07	12	63	1	14	0.07
To educate students with what health information is available to them	14	54	7	54	3	50	4	51	0.99	10	53	4	57	0.99
To discuss student health concerns with parents prior to providing support or teaching adjustments	14	54	5	39	4	67	5	71	0.40	11	58	3	43	0.67
To take on the role of a parent during school hours	8	31	3	23	1	17	4	57	0.29	8	42	0	0	0.06
School role [a]														
To provide a safe environment for students	23	89	11	85	6	100	6	86	0.99	18	95	5	71	0.17
To ensure teachers are well informed of health information that could affect learning and behaviour at school	25	96	12	93	6	100	7	100	0.99	11	58	6	86	0.99
To minimise infectious illness	21	81	10	77	5	83	6	86	0.99	16	84	5	71	0.59
To ensure the school environment fosters learning	17	65	8	62	6	100	3	43	0.11	13	68	4	57	0.66
To ensure parents are well informed of what sensitive information has been passed on to teachers	17	65	8	62	6	100	3	27	0.11	18	95	7	100	0.36

[a] Reflects the number and percentage answering "yes" to this question.

School Roles

Almost all participants believed that the role of the school was to keep parents informed about what information has been passed on to teachers, indicating the need to include parents (n = 25, 96%). Other school roles included the role to provide a safe environment to students (n = 23, 88%) and to minimise infectious illness (n = 21, 81%; see Table 5.3). There were no significant differences between participants from different schools and performing different roles.

Concerns of Sharing Student Health Information

The concerns of sharing student health information were also discussed, with 69% (n = 18) of participants having concerns with how sensitive the information was that was being shared. Over half of participants were concerned with unfairness (58%), whether teachers were trained to handle or access health information (58%), and potential labelling of students and/or whānau (54%). Less than half were concerned about other measures (see Table 5.4). No significant differences by participant role at school or school was found in any of the answers given (FET, $p > 0.05$).

Benefits of Sharing Student Health Information

Participants were asked to think about the benefits of sharing student health information. Every participant noted at least one benefit of sharing student health information. Participants believed that teachers' ability to act in a health incident (85%, n = 22) and support the whole student both physically and emotionally (81%, n = 21) were significant benefits to sharing health information. Only 31% of participants thought that by sharing student health

information, teachers would be able to prevent children from getting unwell (n = 8). More kaiako participants saw the ability for teachers to adjust teaching as a benefit (n = 17, 89%) than other education stuff (n = 3, 43%; FET, p = 0.03). No other significant differences by participant role at school or school were found (see Table 5.4).

Do the benefits and value of sharing health information outweigh the risks?

Near the end of the questionnaire, participants were asked to rate their agreement with the statement: "*the benefits and value of sharing health information outweigh the risks*". Twenty participants indicated they agreed and strongly agreed that the benefits and value outweighed the risks of sharing student health information, with no significant differences identified between schools or between the roles of participants (see Table 5.5).

Thematic analysis of participant explanations and comments

A total of 76 comments were made by 23 participants (88%). Seven comments (11%) were discarded as they were unable to be analysed (e.g. "*I have no further comments*"). Inter-rater reliability was also completed on the 69 remaining comments, with a final consistency rate of 94%. Four (6%) comments were discussed with another doctoral researcher due to disagreement on which theme the comments best fit. Two of these comments were reviewed and incorporated into other existing themes, with the researchers agreeing the other two comments best fit in the original theme.

Table 5.4

Teacher's perceived concerns and benefits of sharing student health information with schools and teachers

	Overall		School						FET, p-value	Role				FET, p-value
			A		B		C			Kaiako		Other Staff		
	n	%	n	%	n	%	n	%		n	%	n	%	
Perceived concerns [a]														
Some medical record information is sensitive/don't want all the information to be shared	18	69	10	77	4	67	4	57	0.75	13	68	5	7	0.99
Unfairness if information has been shared but parent unable to access the information themselves	15	58	7	54	4	67	4	57	0.99	12	63	3	43	0.41
Teachers not trained to handle or access health information	15	58	9	69	3	50	3	43	0.52	10	53	5	71	0.66
Labelling the student or whānau based on a diagnosis in their medical records	14	54	6	46	5	83	3	43	0.27	11	58	3	43	0.40
This information is tapu and needs to be respected	9	35	6	46	1	17	2	29	0.57	5	26	4	57	0.19
Discrimination/disadvantaging the student	8	31	5	39	2	33	1	14	0.56	6	32	2	29	0.99
Teachers are then required to act in a medical incident	8	31	4	31	2	33	2	29	0.99	5	26	3	43	0.64
Parent cannot control who sees their child's health information	8	31	4	31	2	33	2	29	0.99	7	37	1	14	0.38
Parent can't control what information is shared	7	27	4	31	2	33	1	14	0.73	6	32	1	14	0.63
Teacher not comfortable with accessing health information	6	23	2	15	2	33	2	29	0.58	5	26	1	14	0.99
Perceived benefits [a]														

Teacher will know what to do in a health incident	22	85	11	85	5	83	6	86	0.99	17	89	5	71	0.29
Teacher are to support the whole child, physically and emotionally	21	81	9	69	6	100	6	86	0.45	16	84	5	71	0.59
Teacher can adjust teaching to consider health concerns	20	77	8	62	6	100	6	86	0.20	17	89	3	43	0.03
Teacher will understand child's health background	20	77	8	62	6	100	6	86	0.20	16	84	4	57	0.29
Helps explain learning concerns	19	73	9	69	6	100	4	57	0.22	16	84	3	43	0.06
Able to ensure infectious illness is managed at school	15	58	7	54	5	83	3	43	0.35	12	63	3	43	0.41
Gives teachers immediate information when/if needed	15	58	6	46	4	67	5	71	0.59	13	68	2	29	0.10
Teacher able to prevent child from getting unwell	8	31	4	31	2	33	2	29	0.99	8	42	0	0	0.06

[a] Reflects the number and percentage answering "yes" to this question.

Table 5.5

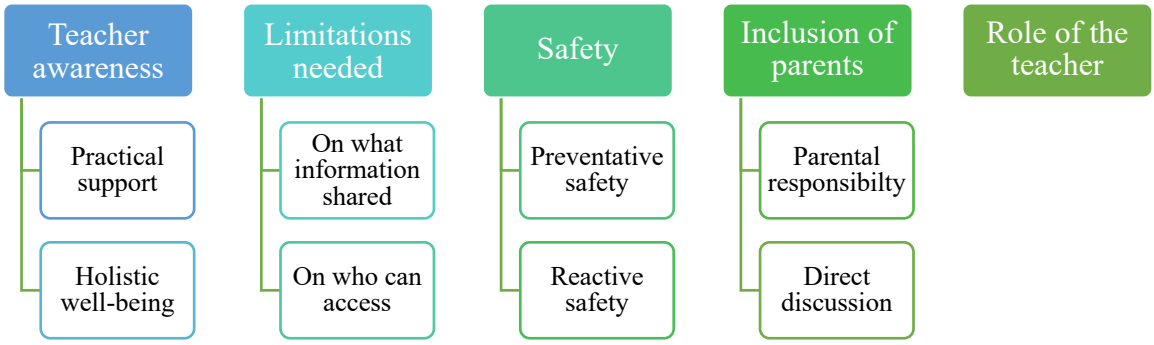
Do the benefits outweigh the risks of sharing student health information?

Response	Total		School						FET p-value	Other Staff		Kaiako		FET p-value
			A		B		C							
	n	%	n	%	n	%	n	%		n	%	n	%	
Strongly Disagree	0	0	0	0	0	0	0	0		0	0	0	0	
Disagree	2	8	1	8	0	0	1	14		0	0	2	11	
Neither Agree or Disagree	4	15	4	31	0	0	0	0	p = 0.54	2	29	2	11	p = 0.23
Agree	14	54	6	23	4	67	4	57		5	71	9	47	
Strongly Agree	6	23	2	15	2	33	2	29		0	0	6	32	

Thematic analysis of 69 comments and explanations was undertaken covering each section of the questionnaire. Five key themes were identified, all of which were previously identified in phase one in the previous chapter and were consistent across the questionnaire (see Figure 5.1). The majority of the comments were made in the first two questions of the questionnaire regarding teacher access and teacher awareness (55%), with a further 19% comments being made in the final comment section of the questionnaire.

Figure 5.1

Themes and sub-themes discovered in Phase 2A



Teacher awareness

The *teacher awareness* theme describes ways for teachers to utilise student health information which supported both learning and well-being. The theme was identified in the teacher access and teacher awareness questions, the benefits of health information sharing, what health information should be shared, in the final comments section. *Teacher awareness* incorporated two sub-themes, *practical support* and *holistic well-being*. *Practical support* considered how teachers could make adjustments for learning ("*different medical issues need different teaching approaches" – Participant 308*). In contrast, holistic well-being considered teachers would be able to provide support for factors outside academic learning *("…provides understanding of that child and a more holistic view"* – Participant 203).

Limitations needed

The *limitations needed* theme was incorporated into all questions except questions that considered the benefits and role of the teacher and school. Similar to phase 1, this theme picked up on the grey area between binary answers (the if's and but's). This grey area is where specific information may or may not be shared based on the nature of the data and why the data is being used. It considered two subthemes. The first discussed *limitations on what information is shared* based on whether the data was sensitive or high risk *("… specific information that is not appropriate to have shared for example children who are under the umbrella of STOP[12]" – Participant 206*), or ensuring the information was relevant ("*anything that affects well-being and learning" – Participant 203)*. The second sub-theme discussed limiting shared health information to certain professionals, ones who have the higher authority or more contact with the student ("*principal first and then… can be opened up to those who need to know including the team leader and teacher" – Participant 303*)

Inclusion of parents

The *inclusion of parents* theme encompasses the need to include parents in the conversation when sharing health information. The theme consists of two sub-themes, *direct discussion* and *parental responsibility.* The *direct discussion* subtheme highlights the vital component of parents and whānau relationships and ensuring they are aware of what information has been shared, and how it is being used (*"…I would hope that schools and teachers have developed relationships with whānau…" – Participant 204*). The *parental responsibility* subtheme

[12] The STOP organization provides community-based assessment and intervention services for children and adolescents engaged in harmful sexual behaviour (STOP, n.d.)

encourages parents to provide informed consent and disclose the information when they see fit (*"…caregivers are respected with whatever is shared with the school…. Must be signed by whānau …and kept confidential" – Participant 196*). These comments emphasized the importance of the teacher-whānau relationship and fostering this relationship when sharing health information, which was not mentioned in phase one.

Safety

The *safety* theme covered preventative and reactive safety, where schools could make adjustments that keep children safe and react to medical incidents (*"…we need to know any medical issues we may be dealing with in order to attend to the needs of the student" – Participant 308*). The need for preventative safety was highlighted when thinking about what information should be shared, such as *"life threatening conditions" (Participant 196)* or information that needs to be shared to keep other children safe. The *safety* theme covers one of the potential benefits of sharing student health information, for both the students themselves and school staff.

Role of the teacher

The *role of the teacher* theme discussed the differing roles and expectation teachers have in providing a safe environment, that fosters learning and well-being (*"…it could be beneficial to our role in duty of care" – Participant 105*). Participants raised concerns about how teachers can often be over-extended ("*I am worried about becoming a parent rather than a teacher" – Participant 106).* This juxtaposition of participant views exposes the growing expectations of teachers and the potential impact on teachers if they take on a parenting role at school.

Phenomena not discussed in phase one

Eight comments discussed phenomena outside the themes from chapter four. The majority of these comments considered the implementation of a health information sharing system (n = 5, 63%), and how the implementation needs to be "…e*fficient… to support this level of information sharing*" *(Participant 194).* Any action must be what is "*best for the children*" *(Participant 107)* and the interests, needs and care of the child and whānau a priority. Participants also mentioned benefits and concerns that were not prescribed answers in the questionnaire. These benefits and concerns included the ability for a DSHISS to extend teacher and school support to whānau, ensure teachers are prepared and give children the best opportunities to learn:

> *"As a new entrant teacher, I feel that we need to be so well informed to ensure that children get the best possible start to school and that we do not have any surprises. We can best prepare our environment for the child and well informed so that we can support the child, parents and those concerned" – Participant 302*

Participants discussed concerns with the current lack of an automatic health information sharing system. They noted that "*at times we have not had access to health information and in some cases have had to ask parents could there be a possible health issue when we have had concerns" (Participant 101).*

5.2.3. *Implications for Phase 2B – focus group interview schedule creation*

The main aim of phase 2A was to create an interview schedule that allowed more in-depth discussion into areas of interest or where participants could expand explanations. The

questionnaire ignited the idea of sharing student health information, with the focus group allowed their ideas and beliefs to come to life.

The "only if..." explanations to the teacher awareness and access questions carried through phase 1 and 2A required attention in the focus group discussions. The researcher asked what limitations were needed to minimise risk to increase the depth of knowledge around these exceptions.

The roles of the teacher, school and parent were discussed to ask participants what appropriate use of health information looked like and how to implement a DSHISS appropriately. Other themes and sub-themes picked up in phase 1 and 2A required more discussion to confirm what teachers meant by providing social support, and how to include parents into the conversation of student health information sharing. It is also essential to look into how the implementation of an information-sharing system could exist ("*efficient systems for sharing and access… to support this level of information sharing")*. Participants may have solutions to any risks, or preferences to how this system could be developed, which can be discussed in the focus groups as a problem-solving task.

5.3. Phase 2B – Focus Group Interviews

Phase 2B aims to expand on the knowledge gained in phase 2A and develop themes that better describe the beliefs of teachers around sharing student health information. Focus group participants will be able to discuss the benefits, risks and implementation of a data-sharing system that could impact them in their teaching positions.

5.3.1. *Method*

Participants

All participants were recruited after indicating they were interested in participating in a follow-up focus group via the kaiako questionnaire used in phase 2A. Those who indicated they would be interested were contacted via email or phone with a time to meet. Snacks were provided, and each participant offered a small koha (gift). Seven of eight interested participants participated in either one of the two focus groups (88%).

Interview Structure Development

Interviews followed a semi-structured approach and addressed ongoing themes identified through the respective questionnaires in phase one and 2A. Five topics of discussion were developed, and a description readied to stimulate conversation about each topic (see Appendix D.2). Each description ended with an open-ended question that allowed participants to discuss their thoughts in depth. The interviewer gave participants time to fully develop their answers and allow for connections to be made between critical ideas and topics. Some questions were disregarded if the participants had adequately discussed them.

Each topic had key phrases or ideas identified. Themes and sub-themes from phase 1 helped develop these key phrases, for example, teacher awareness under the benefits heading (following the identification of teacher awareness as a benefit in phase 1 in chapter four). If the participants did not discuss these key phrases, the interviewer bought them up when and where appropriate. Prompts were developed to encourage participants to expand their ideas about a topic they were discussing. These included gestures, words in agreement and questions to ask them to explain or expand on their points.

Procedure

Two focus groups followed a similar process. Both focus groups were conducted in the participant's school for both ease and the ability to talk in an area the participants were comfortable. The researcher provided both focus groups with a small platter of kai (food) and had a general conversation to help ease any nervousness the participants may be feeling. Two voice recorders were used to record the conversations. Before the recording started, the researcher asked participants to come up with a pseudonym to be used in the write up of this research and asked for their written consent (with their real names). These pseudonyms were dictated by participants and included names of fruit. A description was given about privacy and confidentiality to ensure the participants were clear about the expectations to keep each other's views protected. Once the recording began, participants gave verbal consent under their pseudonym, and the research described how the focus group would be run.

Both focus groups followed an interview guide (see Appendix D.2). This guide helped structure the interviews and provided the focus group five points for discussion which cover risks and benefits of student health information sharing and the roles of parents, teachers and schools. At the end of the focus group, each participant was allowed to add any closing remarks, ask questions to the group or summarise their thoughts. The recording ended, and participants thanked and given a small koha to show the researcher's appreciation for their participation and time. Consolidated criteria for reporting qualitative studies by Booth et al. (2014) were utilised in the write up of phase 3B.

The first focus group was held at School A and five of the six teachers from School A who were interested in participating attended. This focus group was held in a small room inside

the junior area of School A straight after school and lasted 80 minutes. Three of the four teachers from School B and C who were interested in participating attended the second focus group. This focus group was held in the staff room at School C over an hour after school had finished and lasted 50 minutes.

Data Analysis

Similar to the data analysis employed in phase one, phase 2B follows Braun and Clarke (2006) recommended thematic analysis procedure (mentioned in more detail in chapter 3.4). Figure 5.2 explains the key steps in the thematic analysis utilised in phase 2B.

5.3.2. *Findings*

Demographics

Eight participants across three schools from phase 2A were invited to participate. Of the eight, seven attended a focus group (88%). All participants were female, aged between 38 years to 64 years old, and had been teaching between 1 to 45 years. Participants identified mainly as “NZ European/Pākeha” (71%) with one participant identifying as “Māori” and one as an “Other Ethnicity”. Three participants were headteachers of the year 0-2 classrooms, while the remaining four were teachers of year 0-2’s.

Thematic analysis of focus groups

The four final themes identified and described the changing roles of parents, teachers and school, the benefits and risks of sharing student health information, and the solution-focused implementation of a student health information sharing system (see Figure 5.3). Participants were generally positive about the idea of health information sharing, however, all had

concerns about potential risks. These concerns displayed the inner conflict participants had in negotiating the benefits and risks.

Figure 5.2

Process of thematic analysis for phase 2B

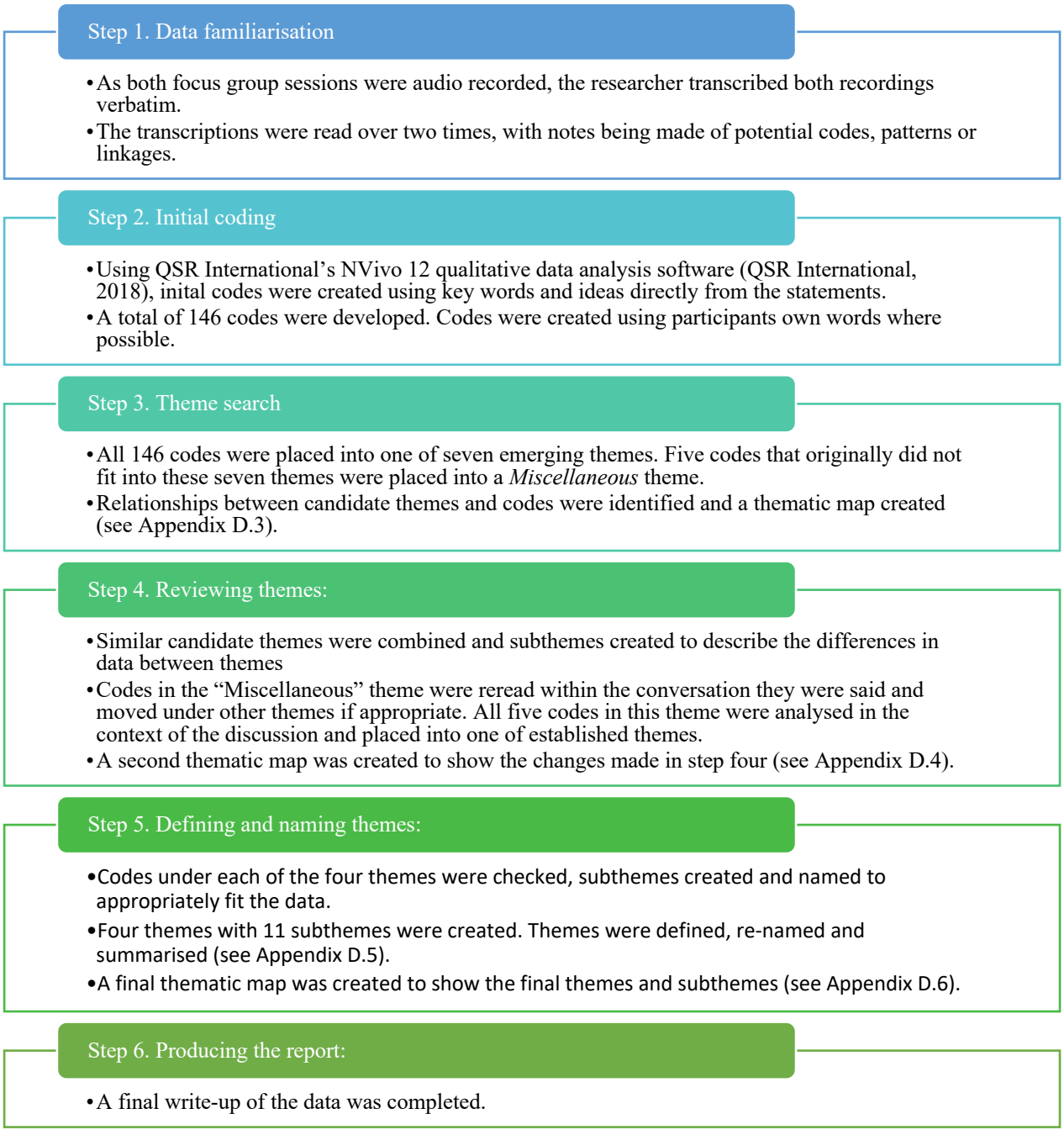
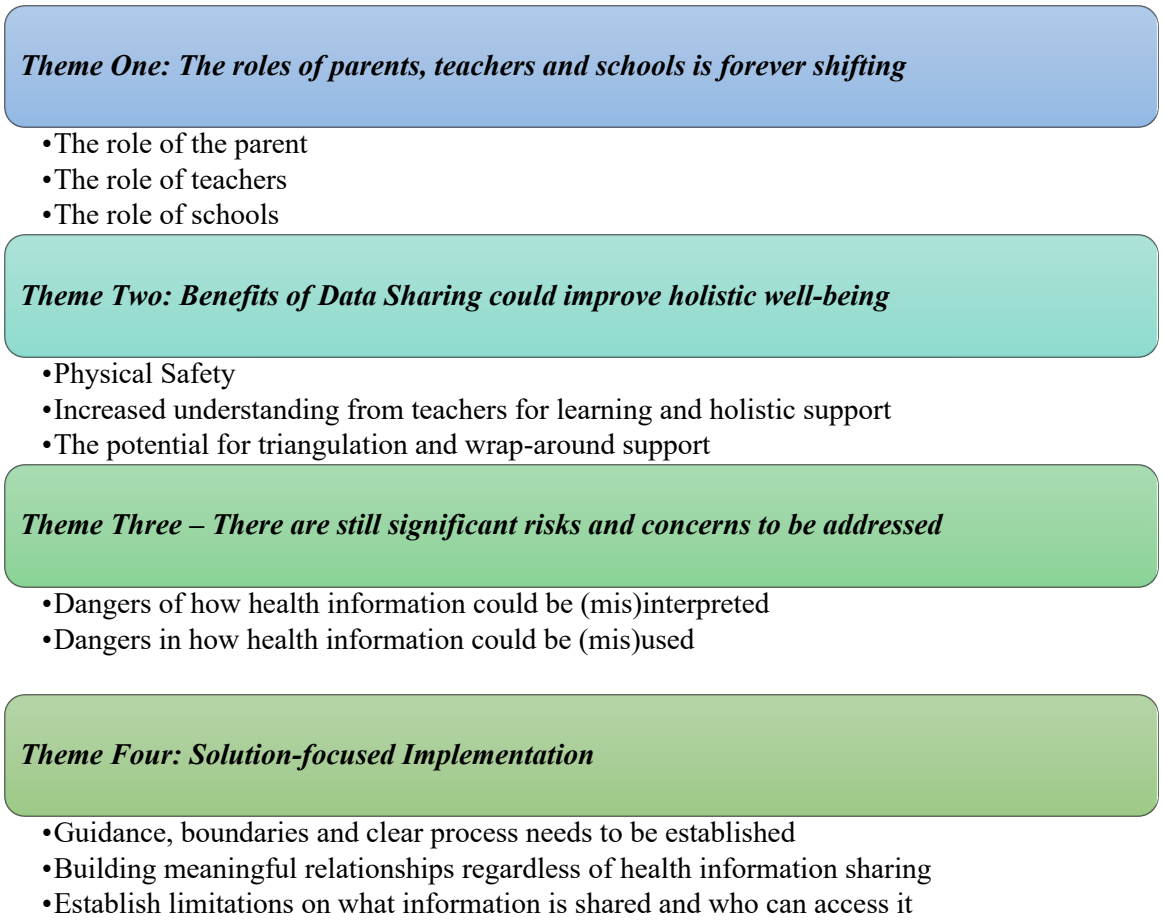


Figure 5.3

Teachers' beliefs toward health information sharing - themes and sub-themes



Theme One – The roles of parents, teachers and schools is forever shifting

Participants discussed how the roles of parents, teachers and the school were evolving, with teachers becoming more "*holistic practitioners" (Belle – School B)* and schools being responsible for more than buildings for education purposes. Participants raised concerns around the need for clearer boundaries ("*…when is it the parent's role to take the child to the doctor rather than the teachers' role … those boundaries, for me, are … blurred… who's responsibility is it?" - Pineapple – School A),* highlighting the need for discussion about

where teacher roles at school begin and end. Three sub-themes were created to discuss the parent, teacher and school role in managing and sharing student health information.

Parent Role

The *parent role* sub-theme discusses the role of a parent to protect and give consent for student health information, as well as the role parent(s), or whānau have on managing, maintaining and providing support for their child's health and well-being. Participants discussed the extent of parental responsibility within a DSHISS. Parents have a responsibility to be caretakers of their child's health information. Participants also discussed how trauma that directly impacted the whānau, can also impact the child:

> *"maybe the children haven't been physically abused but maybe the parent has, … there's an impact on that… last year's year group with the earthquakes you know, that they experience it through their parents really and when they were in-utero" – Wendy (School B)*

Participants discussed the role of parents in ensuring children could access adequate healthcare. They acknowledged how this role could be difficult for parents, particularly in accessing health services and considered the possibility for the education sector to assist in overcoming barriers to accessing healthcare

Teacher Role

Participants discussed how they felt "…*like the role of the teacher is changing" (Arat – School A)*. They believed they had added responsibilities or jobs:

> *"we are now health care providers" – Belle (School B)*

"we are data analysts" – Wendy (School B)

"we are holistic practitioners" - Belle (School B)

Participants believed "*the focus needs to move now away from um, a purely academic, knowledge-based role that teachers were known for, to more of a nurturing, social work, counselling type role…*" *(Arat – School A)* which enables teachers to share information in this capacity. Participants were concerned about the lack of guidelines around teachers taking on actions that were not their responsibility or role:

"…boundaries for me, are still a little bit blurred because is it really my job to take the child to the doctor… whose responsibility is it?" – Pineapple (School A).

The concept of blurred boundaries was raised in both focus groups and highlighted the overlap of roles between parent and teacher. This finding is compacted by some participants believing that they are, "*especially in our years, not just a teacher, you are a parent" (Sue – School B)*.

School Role

Only five comments were made regarding the school's role as participants focused on discussing the role of teachers and parents. Comments made about the role of the school in managing health information discussed immunisations, with many believing the school should be aware of those who have and have not had their immunisations:

"even if the school knows… at least somebody knows" – Sue (School B)

Participants acknowledged how the role of the school has changed in recent years, and how this change often reflects the changing needs of the community:

> *"the community has changed; the needs of what children need at school is changing" – Arat (School A).*

These comments emphasise that schools need to reflect their environment and community, with schools working together with communities to overcome barriers students may be facing, ensuring a sense of inclusion and cohesion.

Theme Two – Benefits of Data Sharing could improve holistic well-being

Participants established the value of sharing health information by discussing the benefits the system would have on their teaching, and for students and whānau. Challenges in sharing student health information often occur when the student is transitioning from ECE to primary, and *"...some of our hui's that we've had around enrolling…it's really difficult to get everyone in the room together to share all that kind of stuff" (Passionfruit – School A)*.

Some parents are unable to share all of a student's health information due to the complex needs of the child, where there were "*... so many things that needed to be considered that her mum didn't actually communicate all of them except the top ones, off the top of her head to start with" (Pineapple, School A).* School A also discussed particular challenges in attaining information within current practices due to the transience of the population leading to potentially life-threatening consequences:

"…because a small proportion of the children are transient, um, you know maybe for whatever reason we didn't find out that information that they were allergic to a nut…" – Arat, School A.

While teachers may be able to identify certain health concerns and then discuss these with parents, the student faces managing their health at school until the teacher is aware of the health concern and can implement appropriate support. This delay can cause the student to fall behind their peers and negatively impact academic achievement. Participants discussed their own experiences with delays in important health information being shared ("…*this was about term two or so down the track…" – Belle, School B*). Participants highlighted that health concerns for one student could also impact other students in the class, both in terms of their learning and their safety:

"any information about sexualised behaviour is useful to us, because those children can affect other children" – Stella, School A

Until the information is shared, teachers often are not able to prepare appropriate support:

"…had we known something beforehand we could have been prepared and… had learning support for them put in place straight away, had meetings with parents but, there was none of that" – Belle, School B

Participants considered the changing nature of health, pointing out that health information sharing needs to be a continuous process that occurs throughout the child's schooling, not just at enrolment ("…*we need to know when things change… it wasn't on any of our information do that was a new, that could have been…anaphylactic…" – Passionfruit, School A).*

Without proper procedure or a DSHISS, there is a risk for teachers to receive information

second hand, which may result in incorrect adjustments as well as the potential for judgement and other risks (*"a lot of the information that we do hear is from people in the community telling us second hand" – Arat, School B)*.

Physical safety

Similar to the findings in chapter four, sharing health information meant that teachers were better able to provide preventative and reactive safety. Participants discussed physical safety, where being aware of certain student health information meant they, as teachers, could be aware of life-threatening medical conditions, for example, "*allergies to nuts… [that could] potentially save a life" (Arat – School A).* Students who were not immunised could benefit as schools would be able to identify those at risk of contracting an infectious disease (by their immunisation status) and talk to parents about keeping the student safe and healthy:

> *"…we know that, that child, has not been immunised against whooping cough, we can take measures and talk to those parents… maybe its best you keep your child home during this time…" – Belle (School B)*

The risk of students hurting other students could also be minimised when teachers are aware, particularly where the student may be experiencing "*conditions that see them lashing out in a physical way" (Wendy, School B)* and the teacher is better prepared to de-escalate the student's physical behaviour because this information is shared in advance. The benefit of preventative safety also extends past the students, but to the staff as well:

> *"…if they've been hurting the parents at home, and they get very physical and violent at school, they do the same thing to the teacher…" – Belle (School B)*

By being aware of violent behaviour, teachers and schools can put things in place to minimise this behaviour, keeping both students and staff safe.

Increased understanding from teachers for learning and holistic support

Sharing student health information with teachers was perceived to enable teachers a better understanding of their students. By having student health information, it:

> *"...gives you a really good perspective of why the child is behaving the way they are behaving. It's not because they were on the spectrum… it's because of... trauma that they, that they have pretty much bought themselves up… if you know the history, or if the conditions are actually disclosed to you, it definitely can help the situation, with the way that you respond and how you can help the children" – Pineapple (School A)*

Without this greater understanding of a child's background, teachers may make incorrect conclusions about a child's behaviour and act on incomplete or incorrect information. A DSHISS allows teachers to spend less time trying to figure out what the child needs and more time preparing and supporting students and their health needs.

Another benefit of a DSHISS is the improved ability for teachers to provide appropriate and prompt learning support. Participants discussed how if they had known about a medical condition in advance, they could provide "…*learning assistance starting from day one*…" *(Wendy – School B),* and "…*learning support for them put in place straight away*…" *(Belle – School B)*.

Teachers can prioritise what support was given based on health information, and with this knowledge comes the ability of the teacher to support students in the best way they can:

> *"…there's different priorities for a child who has seen violence, or has experienced trauma then… there's different priorities in the way that you educate them" – Arat (School A)*

As well as practical teaching support or learning assistance, schools and teachers can provide holistic support for well-being. Participants considered their role as new entrant teachers, who often have to provide safety and security to the students:

> *"… they're here to feel safe, and loved and that's a huge part, and every child deserves that regardless of where they have come from…" – Wendy (School B)*

as well as support the "… *social and emotional needs of the children…" (Passionfruit, School A),* and be advocates for their mental health and well-being. They discussed the need to consider the *"…whole child" (Wendy, School B)* and that sharing health information would help fully understand the child and how best to support them.

The support given by teachers and schools can be available not only to students but also to students' whānau. Participants highlighted the need to support the student's whānau as well:

> *"…support the families so they can send their child to school… a family is feeling like they are all alone, and some other family has said…is there anyone else, um, you could ask if they want to be put together to have a chat, or that would benefit…"– Wendy (School B)*

The potential for triangulation and wrap-around support

Participants considered students transitioning between early childhood education centres and primary school, discussing how sharing student health information between preschool and primary schools helped ease the child's transition:

> *"… preschools get in touch with us. You might get in touch with preschools. Preschools do come and do some visits, or we might go and do some preschool visits… it would help the preschools in schools to have more communication with each other…" – Belle (School B)*

Participants discussed the idea that by sharing student health information students would be better supported by collaboration between involved organisations. Participants discussed how by sharing health information, organisations and agencies that offer support services, such as Oranga Tamariki, could provide integrated support that complements each other. This integrated support is particularly important when a student and their whānau is involved "*…in a lot of agencies" (Passionfruit – School A)* as:

> *"… the parents and the school need to work together, and the counselling and social services. There needs to be a triangulation of help for the very best outcomes … I don't think we have that model at the moment… I think we are still very in bits and that's why we're struggling so much…" – Arat. (School A)*

Participants discussed how triangulation of services, and even just having that information shared with teachers meant there was a better ability for maintaining "*consistency around managing the behaviour…*" *(Wendy – School B)*, with emphasis on consistency between school and home:

"… With mental health and all those sorts of things too, consistency and uh, routine really helps the situation so if everybody is aware of what's going on, you can make sure you know, you do and IEP whatever is needed and all the key people in the child's life at together, sorting out what's important, how it's going to work…" – Wendy (School B)

That consistency involves working with organisations and parents, to create action plans for home and school, which can be facilitated through a DSHISS.

Theme Three – There are still significant risks and concerns to be addressed

Consideration for the benefits of a health information sharing system also bought up potential risks. Theme three considered what concerns whānau, teachers and communities may have with the implementation of a health information sharing system by identifying risks which are essential in order to overcome them. It also triggered thoughts from participants to consider other stakeholders' points of view and think outside their roles as educators.

There are many reasons why parents do not share information with teachers, and these reasons often reflect the perceived dangers of sharing health information. Participants discussed why they thought parents did not share information and came up with two main reasons; 1) bad experiences, or stories of bad experiences, deter sharing information and; 2) parents may be uncomfortable in sharing.

Many bad experiences centred around Oranga Tamariki. Participants noted that many whānau "…*have had a lot of disappointment, and a lot of knock backs in their lives and they don't want another one*" *(Passionfruit – School A)*. Parental concerns around government

intervention, particularly Oranga Tamariki, further fuels the adverse perception of sharing information between government sectors, with parents concerned that teachers may make incorrect judgements that lead to unnecessary intervention:

> *"... sometimes I know that from experience that if you have children on the spectrum, or you have children who are different, then OT [Oranga Tamariki] can get called because people think they're screaming or whatever ..." – Arat (School A)*

Parents can also worry about how they may be perceived if their child's health information was to be shared ("…*posher parents didn't want us to know that their children had conditions like ADHD because they didn't want it to become common knowledge" – Stella, School A*). This fear of negative perceptions is especially salient if there has been prior intervention from government agencies:

> *"... I think some of them don't speak up and the enrolment procedure, because of that. I don't want to sit there and tell you they have been involved with this agency and this agency" – Arat (School A)*

> *"... some parents are willing to share everything about the child, but then I can think of so many families that wouldn't because of your home-life background. Because of what they've done, their choices, have contributed to the way the child is..." – Belle (School B)*

While participants thought some parents do not see value in sharing information or just are deterred by the potential of a negative outcome (*"... so there is a real fear that we could have*

that power to do something negative, which you know, which would affect, would influence them…"– Arat, School A).

Dangers of how health information could be (mis)interpreted

Participants discussed how teachers may be unable to remain partial to health information and harmful conclusions made based on the health information that is shared with them. Stigmatising or judging the student based on the student's health information was a concern across focus groups. This concern is not limited to children only but also whānau and parents. An example of how a teacher may judge a parent based on the child's foetal alcohol syndrome diagnosis was highlighted in the focus groups:

> *"because I, me as the mother, I was the one who drunk too much, or drunk while my baby was in-utero, there's stigma against parents, I know that your child has… foetal alcohol syndrome" – Belle (School B)*

Participants discussed how with *"…judgement comes a fear of being excluded, that they are not going to be wanted within that learning community… there's a real fear that there's nowhere [to go] if they disclose everything…" (Passionfruit – School A)*. There is also concerns about whether teachers might *"…read it [the student's health information] wrong or assume something" (Arat – School A), "…think differently about me or my child [or]…treat my child differently" (Wendy – School B).* The fear of judgement and repercussions is given as a reason whānau do not share student health information currently.

Dangers in how health information could be (mis)used

Building on from the above sub-theme, the dangers of how information could be misused also came up across both focus groups. Participants discussed the idea of human flaws, where "*people are people aren't they. And some people talk more than others…I don't know how you overcome that" (Pineapple – School A).* Along with confidentiality breaches, there was concern that schools could misuse the information:

> *"… by looking up the family and them going, oh, that family has a whole heap of history…would schools misuse it like that? Then they would go, oh no sorry, come up with an excuse…" – Arat (School A)*

This misuse could be particularly relevant when a parent wants to enrol their child *("… they're vetting it and going sorry, we can't take your enrolment, we are actually a bit full" – Pineapple, School A).*

There is a potential for teachers to misuse shared health information by making inappropriate adjustments, or not taking expected actions that consider the student's health. This action, or in-action, could be through "*over-compensating when you are treating them as too precious instead of…."(Sue – School B)*, or not using the information at all ("*…I have shared information about my daughter, and it's been ignored… you just lose hope in the system because you do share information and it sits there and nobody pays it any attention"- Arat, School A).*

Theme Four – Solution-focused Implementation

When participants discussed the concerns and risks of sharing student health information, many offered solutions and ways to manage the risks. These solutions were often raised without interviewer prompts. Three main subthemes were created to understand solutions put forward by participants. These subthemes included what information should be shared and who should be able to see it, the importance of building meaningful relationships with whānau, and the need for clearly established processes for access that empowers teachers to access and use the information effectively and appropriately.

Guidance, boundaries and clear process needs to be established

Participants considered how a student's health information might be accessed and whether they should only access the information after the teacher has raised a concern. This solution was one way to minimise prejudice from health information sharing and give students the chance of a clean slate. Participants highlighted that in some children, they refuse to read information from prior educators:

> *"...I often refuse to read the information that comes with the child...*
>
> *because I want to give them a fair go ..." – Arat, School A*

It was made clear by participants that "*you can only access the information after*" *(Passionfruit – School A)* enrolment, "*definitely not before…*" *(Arat – School A)* to ensure schools cannot use the information to exclude students from attending.

Participants discussed accessing information after a valid request was made *("...you could apply for the information…I'm requesting further information to check whether this test has*

been done or whether it could possibly be this…"– Arat, School A) safeguarding invalid reasons where information may be misused and putting the responsibility on teachers to take ownership. Participants raised concerns with the current lack of resources, especially if there was another process to follow to access the information each time *("...nothing puts a teacher off more than more paperwork" – Stella, School A).* This finding highlights the potential increase in paperwork and resourcing barriers to required accessing and utilising a DSHISS.

Participants were also concerned about knowing how to use the information ("*I really don't know what we would do with it…*"*– Stella, School A*) emphasising the importance of health information sharing for valid and explained reasons and with guidance on how to use the information effectively. Participants discussed how there seemed to be a mismatch around the level of professionalism expected of teachers compared to the information teachers were privy too ("*...every teacher keeps a level of professionalism..." – Wendy, School B*) Participants also highlighted that teachers "*…need as much information as we can and we have to be trusted as professionals*" *(Wendy, School B)* with this information.

Some comparisons were made to Early Childhood Education (ECE) around policies for immunisation status being shared, with participants noting that "*…in early childhood* [education centres] *it is mandatory to keep an immunisation register… It's got a tick, tick, tick, what have they had or not… there's no pressure" (Passionfruit, School B)*. Participants did not realise that this procedure was not mandatory in New Zealand primary schools ("*Do we have that here?" – Arat, School A*, "*No, so we don't have any immunisation proof at all*" *– Passionfruit, School A*). Participants noted that different year-levels might require different information to be shared:

"... I wonder what the year six teachers would think or say, because they have things like about puberty, things like if girls have started to their period, is that anyone's business? But actually, it is, it is kind of your business, it explains a lot" – Sue, School B

This comment considers the complexity of health information when a child ages and asks questions around when a child is capable of making their own decision around sharing health information and at what age they are capable at giving consent.

Building meaningful relationships with whānau

Participants from both schools discussed the importance of establishing and maintaining relationships with their students whānau. Building trusting relationships is a vital aspect to a teacher's job, particularly when it comes to sharing information that is sensitive ("*it's around developing a relationship, so, it is about those trusting relationships, so they feel as if they can share those things*" *– Passionfruit, School A*).

Participants mentioned how important having a relationship with the parents or whānau is to them as teachers ("…*making sure that you build those relationships with the parents as well as the child…*" *– Wendy, School B*). They discussed their own experiences where information was only shared once the teacher and school had built a relationship with the whānau:

"... it wasn't until we had built a relationship with the mum that we found out that that was going on at home and umm, and there's other things as well like... he was wetting at home and that was causing, that was a sign of anxiety..."– Arat, School A

Participants discussed the need to include parents when sharing health information. They highlighted the risk of parental inclusion is better managed when teachers built strong relationships with whānau ("*I guess it depends if you consider it as a loss of control, …again I think it's… developing that relationship and having that trusting thing" – Passionfruit, School A*). Participants believed "…*if you know a bit about the whānau it gives you more empathy*…" (*Arat, School A)* indicating less chance of misuse.

Both focus groups discussed the enrolment process as being a vital step to establishing relationships with whānau through conversation ("…*parents are given opportunity to meet the new teachers and talk to them*…"*– Belle, School B).* Participants saw this process as a chance to empower parents to share information ("… *part of our enrolment process is a hui, so every* [new entrant] *parent has one, it's a conversation and you're not trying to grab information, but empower them to share*…"*– Passionfruit, School A*).

After enrolment, the relationship must be maintained through communication as well as meeting with parents to discuss concerns *("… she was really struggling socially, really struggling making connections with people, and then I had her learning conference with her parents and she was 15 months when the earthquakes happened…"– Wendy, School B).* Having this relationship with parents enables teachers to have conversations that focus on minimising the impact of poor health *("…to get her back to school, I had a conversation with mum… I said if you think she's well enough to be at school, then let us have a turn and we'll do whatever you do to manage it." – Wendy, School B).*

Establish limitations on what information is shared and who can access it

Building on the questionnaire, participants discussed what health information might help their job as teachers. Participants discussed information about hearing and vision as being necessary to share, with some discussing where this information could come from ("*what would be helpful is their hearing and vision testing. … because we get so frustrated with the system, but you can't find any information out… they get a B4SC, we could know that information. We don't at the moment" – Arat, School A*). Participants thought sharing information regarding allergies and life-threatening information was vital *("…allergies is a good one, because it does impact us" – Pineapple, School A)*. Participants discussed toileting issues as vital information that needed to be shared *("a child kept wetting themselves, and later we found out later that they had a history of UTIs… I wasn't telling the parent every time…" – Sue, School B)*. This concern of toileting issues is especially important in those first years of instructed learning, where toileting issues are most prevalent.

Participants expanded on types of chronic or on-going health concerns they thought should be shared with teachers. Both schools discussed asthma and diabetes, perhaps due to the higher number of these conditions, while some less prevalent conditions were also discussed (*"… a child with chronic constipation…"– Belle, School B*). Autism was discussed by participants, noting that some information is harder than others to share ("*Autism… parents sometimes find that really hard too, either say or not to say because of the stigma that goes with it" – Arat, School A*). Sharing information about student's reoccurring acute conditions was also thought to be necessary, "*especially if it can explain absences…"* (*Sue, School B)*.

Mental health and behaviour were discussed, particularly in terms of remaining consistent between home and school, and ensuring that the teacher is aware of the best practice for supporting the student (*"…with mental health… consistency and ah, routine really helps…"– Wendy, School B; "…behavioural issues, and it was to do with, um, what the parents had been doing…it just gives you a really good perspective of why the child is behaving that way… with the way you respond and how you can help…"– Pineapple, School A*).

Trauma and abuse were also thought to be vital information to share with educators. Participants discussed how *"any information about sexualised behaviour is useful to us, because those children can affect other children" (Stella, School A)*, and *"…sexual abuse…that's a grey line as well, you know, you want teachers to be aware, to be sensitive to that child's needs, but there's a need to know basis…" (Belle, School B)*. These comments portray the complexity of sharing sensitive information, mainly the information that potentially has ties to the child's background as it may impact how a child is supported:

> *"…trauma is quite a big one here. So they don't necessarily want to tell us what the trauma is but… if we knew a bit about the trauma that they have been through , would that help us understand, or it might know whether its ADHD or trauma, or it might help us understand more about the pathways that they need to have support to overcome those things, rather than we left sort of guessing" – Arat, School A*

5.4. Discussion

This thesis employed a mixed-method design to provide a better understanding of teacher beliefs and attitudes to sharing health information. Integration of phase 2A and 2B occurred

in two ways. The first saw findings from 2A inform the development of the interview schedule for focus groups in phase 2B. The second integration occurred as data from phase 2A, and 2B was combined, allowing for a deeper understanding of participant thoughts and perceptions. This section addresses the latter, first presenting a summary of phase 2A and 2B and then presenting an interpretation of the integrated beliefs of teachers from the questionnaire in phase 2A and focus groups in 2B. To better view this integration, Table 5.6 displays the data by phase and theme.

5.4.1. *Value and potential of a DSHISS: a kaiako perspective*

Sharing health information has the potential to benefit children in several ways. The ability of greater physical safety was seen as one of the major benefits across both the questionnaire in phase 2A (85%) and focus groups in phase 2B. The importance of providing a safe school environment is mandatory through New Zealand legislation (Ministry of Education, 2017). Having teachers aware of the health concerns of their children, particularly the life-threatening conditions, allows teachers and schools to provide a safe environment and react appropriately in medical incidents and is supported by literature (Student Rights NZ, 2019).

Participants across phase 2 discussed how while the primary task was to support a student's learning, teachers are aware that whānau and student well-being are vital to a student's ability to learn (*"... teaching is not just about the academics, we teach the whole child" – Wendy, School B*). This holistic support considered academic success, positive SEMH development and overall greater well-being. Participants could see significant value in a DSHISS as it facilitates their ability to provide this support and overcomes current barriers that teachers have in providing this support, mainly the delay in being aware of the information needed to

Table 5.6
List of integrated findings in phase 2A and 2B for interpretation

PHASE 2A – Teachers Questionnaire	PHASE 2B – Teacher Focus Group Themes
The roles of teachers, schools and parents are changing • Parents' role is to ensure that teachers are informed of student health (77%), to allow access and give consent to health information (69%, 65% respectively). More teachers from School B and C (100% respectively) expected parents to share health information with teachers and give consent than School A (54%, FET, p = 0.03; 39%, FET, p = 0.02) • A teacher's role focused on providing holistic support (89%), understanding health backgrounds (89%) and acting in medical incidents at school (81%). Only a small number (31%) thought it was a teacher's role to act as parents during school times. • A school's role centred around informing teachers of information that could impact learning and teaching (96%), providing safe environment (89%) that minimises infectious illness (81%) and fosters learning (65%). They also have a part to play in informing parents about what information is being or has been shared (65%)	• *The role of the parent* is to have responsibility for consenting to sharing health information and maintaining their roles as guardians of their child and their child's information. Participants noted that how parents own well-being can impact children at school, and thus having health information might also help whānau • *The role of teachers* has changed over the years, from a purely academic role to a provider of holistic support. Because of the extra responsibilities, teachers are unclear where their role ends. • *The role of schools* are required to respond to the needs of the community as well as be a safe education establishment. This community focus and response to community need highlights need to build relationships and reflect holistically. • *Need to be flexible* in each role but have clear guidelines on where to draw line.

Benefits of Data Sharing could improve holistic well-being

- Safety and ability to act was the great perceived benefit of sharing health information (85%) followed by the ability to support the physical and SEMH needs of the child (81%).
- The majority saw the teacher being more understanding of the child's background and having the ability to make classroom adjustments that considers the health concern (77%).
- Teachers (89%) were more likely to consider their ability to make classroom adjustment based on health information compared to other education staff (43%, p = 0.03).
- Less than a third considered prevention of infectious illness as a benefit of a DSHISS.

- *Physical safety*: increased ability to react appropriately, minimise impact on other students
- *Increased understanding from teachers for learning and holistic support:* resulting in increased preparedness, appropriate classroom management and ability to make meaningful adjustments in the classroom that maximises learning and SEMH development without delays. Support can also be provided/ bought in for whānau
- *The potential for triangulation and wrap-around support*: Sharing info between services that can work together with the sole purpose to improve outcomes for children and their whānau. Improved communication, more cohesive approaches, no doubling up of services. Chance for bi-directional sharing with GPs providing rounder picture of a child's health.

There are still significant risks and concerns to be addressed

- Only four of the ten concerns given had over 50% of participants identify them as concerns around sharing health information.
- Nearly 70% saw the medical information as sensitive being a risk, while 58% were concerned with the lack of training on how to use the information and unfairness that the parents aren't able to access the information as readily. Less than a quarter were concerned that teachers weren't comfortable accessing the information.

- *Misuse and discrimination*: concerns around privacy breaches were high, participants acknowledging the human bias and letting information slip. Participants also considered whether schools would not allow children to enrol because of their health information.
- *Misinterpretation*: some health information can have significant implications on past whānau behaviour (e.g. foetal alcohol syndrome) and if shared, those who are accessing may make unfair or incorrect assumptions leading to judgement. These negative

- Perceived concerns did not vary between schools or roles.

Solution-focused Implementation

- Limitations needed around what information is shared and who with. Some information should be shared readily (e.g. hearing and vision (96%) and life-threatening (96%)) while others are more sensitive (e.g. mental health 88%).
- Teachers were comfortable accessing most information, however found immunisations (54%), oral health (58%) and mental health (73%) with less agreement. Classroom teachers and health stuff considered top of list of who should have access (62%, 58% respectively)
- Significant differences about consent, where teachers believe consent should be opt-out (79%) while other staff believe consent should be opt-in (71%) FET, $p = 0.03$
- Benefits outweigh the risks with 77% agreeing or strongly agreeing with this statement

interpretations can also extend past the information itself and onto where the information has come from in the first place (i.e. Oranga Tamariki).

- Negative past experiences or stories of misuse fuel participant concerns

- *Guidance, boundaries and clear process needs to be established:* allows teachers to better understand the limitations of their role and feel confident they are taking the right step in using health information effectively. Also establishes teachers as professionals and responsible to uphold professional standards.
- *Building meaningful relationships regardless of health information sharing*: by prioritising relationships with whānau not only are whānau better included, the support and interventions can be made collaboratively allowing for clear expectations for the child. Parents can better trust their child's teachers and can see the value in sharing information.
- *Establish limitations on what information is shared and who can access it*: demonstrating that some information may need to be classed differently than others due to sensitivity and associated risk. Careful consideration is needed when sharing with certain educators, with questions around accountability, responsibility and need of the educator to have access.

provide holistic support. Minimising this delay is crucial for many students, so they do not fall behind and is especially crucial in the first year of schooling where children are developing fundamental literacy skills, such as phonetic awareness (Gillon, 2017; Gillon et al., 2019). Teachers would be enabled to make environmental and teaching adjustments that allow children to be better prepared to learn despite their health concerns without children falling behind and missing potential vital teaching (Thies, 1999). Participants viewed these adjustments, along with a greater ability for empathy and understanding from teachers, can lead to increased school success and improved social, emotional and mental health (Cunningham & Wodrich, 2006). Phase 2B expanded on the idea that teachers can support the whole child physically and emotionally, to include the whānau, recognising the integral part whānau and social well-being can impact a student at school. By having this information, tailored support and resourcing can take in to account the child's ability as well as considering the family's and student's social and emotional load at the time.

The opportunity for triangulation with whānau and organisations outside of the school environment was developed purely in the focus groups. Participants highlighted how bi-directional sharing could improve the consistency between services offered by organisations involved in the whānau or child's life, as well as providing consistency between school and home. Remaining consistent is an important factor in managing behaviour, mental illness and health (Herrera & Little, 2005). By ensuring that all the people in a child's life are on the same page on the best way to support that child, the student is given a much better chance of developing positive interactions with these organisations and improving their health and well-being. It also helps smooth the transition between the roles of parents and teachers, and between home and school mentioned above. Triangulation of services is already occurring throughout social development organisations, as well as between sectors, as mentioned in chapter two (Edwards, 2004). These examples of triangulation or

collaboration between organisations demonstrate how participants are justified in seeing triangulation between and within the education, social services and health sectors as beneficial to students and their whānau. Such triangulation could become simpler and more efficient if a DSHISS existed.

Participants across phase 2 recognised the significant value in sharing student health information and were able to picture ways in which it would assist their ability to do their job. The benefits often addressed challenges that teachers currently face, as well as improving the academic outcomes for students. This value emphasises that potential a DSHISS could have. It demonstrates the potential acceptance teachers have toward the system if it were implemented. The emphasise on the perceived value from teachers highlights the impact poor health is having on children in their first few years at school and helps establish the need for an intervention that integrates children's health into the education sector.

5.4.2. *Considered implementation*

Participants across phase 2 displayed generally positive attitudes towards a DSHISS. They also voiced concern that such a system carries significant risks. Despite participants establishing the need and value of a DSHISS, they highlighted the need to ensure that implementation was done the right way, included the right people and for the right reasons.

Teachers, Schools and Communities – the need for flexibility

Discussion around the roles of teachers and schools highlighted the intricacies of each role and displayed the need for educators to be flexible and reflective to their community. Participants eluded that a one-size-fits-all approach to teaching and defining teacher and school roles as such would not

be useful as it does not consider the varying needs and backgrounds of students within different communities.

The role of the teacher has had to evolve alongside their community. They are supporting their students to learn through providing both teaching and pastoral care. As a result, they are improving their students learning and well-being for many children (Lewallen et al., 2015). A DSHISS may facilitate teachers' ability to deliver appropriate teaching and provide targeted pastoral care based on shared information. However, participants highlighted it could also mean that the expectations on teachers grow as more information is readily available, leading to blurred role boundaries and potentially higher workloads on staff who are already thought to be overworked and under-resourced (Arvidsson et al., 2019; Whitehead et al., 2000).

Participants discussed how schools need to reflect the needs of their community to best support their students ("*the community has changed, the needs of what children need at school is changing" – Arat, School A*). While participants saw schools responsible for ensuring teachers were informed of health that could impact learning and teaching (96%) and providing a safe environment for students (89%), the focus groups expanded the role of schools to be community driven. By being more community-focused, they will be able to respond to the needs of their students and their students' whānau and be flexible in this response. Participants believed schools are intertwined with their community. As a result, the roles of teachers or schools are unable to be strictly defined as they must reflect the needs of their community, aligning with literature (Community Schools Alliance, 2019; De Bourdeaudhuij et al., 2015; Dryfoos & Maguire, 2019). As a result, some schools will be more involved with students and their whānau than others, with roles extending at times for a reactionary period (Ministry of Education, 2016), for example when schools were forced to lockdown after the

terrorist attack 15 March 2019. This may mean where parents or home life are unable to support well-being, schools and teachers are well-positioned to help support their student's well-being through providing or facilitating access to services such as GP visits or dental care (Dryfoos et al., 2005).

The need for schools to be active members of the community and maintain role flexibility adds to both the school's role and the role of teachers too. Schools are no longer only required to provide safe, healthy, informative environments that foster learning. Teachers are no longer required to solely teach academic information. Teachers and schools also need to be community-focused, and become more holistic in their practice and consider the needs of the community they are in and how best to work with their community to enhance its well-being (Community Schools Alliance, 2019; Ministry of Health, 2009a).

Participants highlighted how parent must be included if a DSHISS was to go ahead. As the primary guardian, parents have a responsibility to keep their child's information safe and must provide consent for health information to be released (69%). As such, it is important for parents to have meaningful interactions and build trust in the organisations that are asking for consent for health information. Establishing relationships between parents or whānau and teachers was highlighted as a vital to increasing the likelihood of parental consent and information sharing, and is well-supported by the literature (Adams & Christenson, 2000; American Federation of Teachers, 2007).

The risks and necessary considerations

The concerns for misuse and misinterpretation were carried through the questionnaire to the focus groups and must be considered before sharing any sensitive information. Health information could

include incredibly sensitive information that can harm individuals and whānau if it was to be misinterpreted or misused (New Zealand Data Futures Forum, 2017). Labelling and discrimination highlight the potential risks of sharing information and needs to be considered whenever sharing information (Deloitte, 2015; New Zealand Data Futures Forum, 2017). Consequences for misuse can include legal ramifications, loss of employment, and financial penalties (Office of the Privacy Commissioner, 2013). However, once data has been misused, the information is no longer private. Individuals then, need to consider the purpose of sharing information and how to minimise any associated risks.

It is also vital to consider why individuals may be averse to sharing information. Teachers are very aware of parents' cautiousness to share any information, particularly when that parent has had social services involvement, such as Oranga Tamariki. Involvement with social services was found to negatively impact information sharing (Richardson & Asthana, 2005). Experience is an essential factor in the willingness to share information (Davidson et al., 2015). People are often deterred from sharing information when they have lost trust in the system asking for information, either due to their personal experience with the system or when they have heard negative stories about the system (Perera et al., 2011). These stories may be from whānau, friends or media outlets (Bateman, 2019; Sumner, 2019). Understanding the reasons individuals are against sharing information allows identification of areas where trust needs to be fostered to ensure the perceived value outweighs the perceived risks.

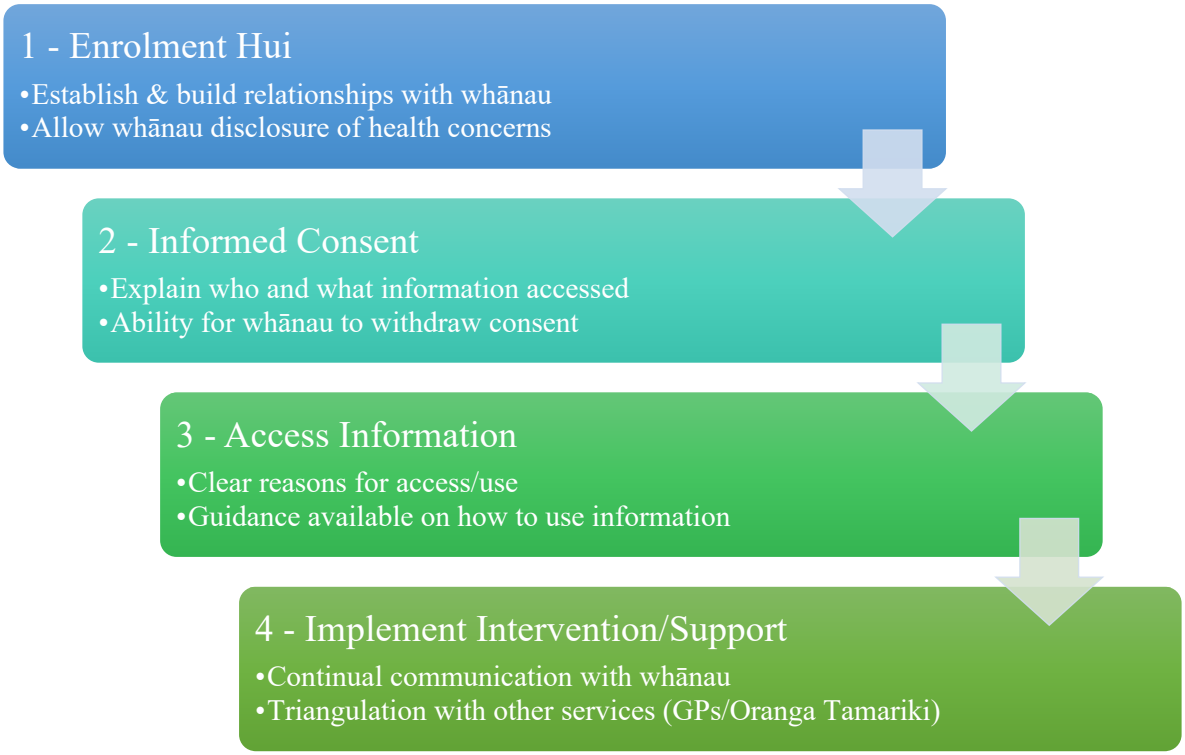
Focus group participants gave several suggestions on how the sharing of student health information could occur. Participants throughout the questionnaires and focus groups highlighted the need for guidance around what can be shared and how to use the information effectively. This guidance

requires procedural oversight and resources, particularly at the implementation stage, to ensure staff feel comfortable and able to access and use the information (Ozair et al., 2015). Resources that provide teachers guidance on how to use the information they have received must be available so that teachers are empowered to use the information effectively (Cunningham & Wodrich, 2006). Minimising any barriers teachers may face in accessing this information is essential. Teachers are burning out rapidly, and a system the shares health information is only going be useful if it minimises the teacher workload (New Zealand Educational Institute, 2019; Whitehead et al., 2000). Further consideration of what information is shared and who can access it will also minimise the risks of misuse (Ozair et al., 2015). Ensuring clear boundaries for who can access it (whether it be teachers, pastoral care staff or senior management) and having defined purpose for this access will keep individuals that are accessing it for insincere reasons abated.

A summary of the potential process in sharing student health information based was developed from recommendations of participants who teach new entrant level students (and is thus most relevant to those students coming into their first year of school; see Figure 5.4). This summary incorporates the need for transparent process and guidelines around shared student health information as well as the need to prioritise relationships with whānau. The first stage begins with a focus on the enrolment hui with emphasis on building relationships with whānau and empowering them to share relevant information about the student. This hui enables the teacher to foster trust, which in turn can allow for greater information sharing (New Zealand Data Futures Forum, 2017). The second stage is obtaining informed consent. Obtaining consent can occur during the enrolment hui. The hui acts as a gateway to receiving informed consent from whānau as it allows teachers to meet parents, to inform parents on the process, safeguards and address any concerns parents may have.

Figure 5.4

Process of sharing student health information – as advised by teachers



After consent is received, teachers can access student health information as long as there is clear reasoning for use. This justified access process would mean only information that was relevant to certain educators would be accessed. Resources for teachers to supplement the information shared is essential in this stage, so teachers are able best utilise the information (Thies, 1999). The final stage allows teachers to utilise the information and supplementary resources to put interventions in place or make adjustments to their practice. By allowing the best practice, and triangulation with appropriate organisations that provide more specialised support, the teacher may minimise the impact of child health concerns on learning while improving overall well-being (Cunningham & Wodrich, 2012).

5.4.3. *Limitations*

This section outlines several limitations and strengths specific to phase 2. The overall strengths and limitations of the entire thesis can be found in Chapter Seven (see section 7.4). Participants were mostly Pākeha (73% from the questionnaire; 86% from the focus group) thus does not adequately represent the multicultural make-up of NZ. This ethnicity distribution limits the ability of the analysis to include Pasifika, Asian or Māori worldviews and thus does not adequately represent New Zealand's growing multicultural environment. Participants were also mostly female in both the questionnaire and focus groups (85%; 100% respectively). While this may not represent the gender distribution of New Zealand as a whole, it does reflect the female-dominant teaching population (85% of primary school teachers were women in 2019) in New Zealand (Education Counts, 2020). All participants in the focus groups were also kaiako, thus there was no representation of other staff within the education sector in the focus group discussion. Future research should include participants from a variety of backgrounds in education and with wider cultural diversity to gain the unique perspectives of a more representative sample.

Several limitations to the questionnaire (phase 2A) exist. The low response rate of other education staff, particularly from School B and C, may have caused bias in the findings. As a result, the research was unable to obtain views of other education staff from the variety of schools it had hoped, which may have impacted the findings. The response rate of teachers was excellent, however, remained a small sample size. By increasing the number of participants, these findings could have been based on a more representative sample. However, the research aimed to discover key stakeholder opinions in-depth, rather than breadth. Including more schools may have increased the validity of this study as participants from different backgrounds, areas and regions around New Zealand may have differing opinions to those discovered in this phase.

The limited number of participants (n = 7) across two focus groups (phase 2B) meant the sample may not be representative of the education professionals at those schools. The third school was also a decile ten school, and thus the analysis in phase 2B did not include a voice from this SES area. Focus groups may also limit a participant's ability to feel comfortable in expressing their views, especially if the group is expressing a tendency toward one viewpoint (Acocella, 2012). This limitation may have been further exacerbated in these focus groups as the headteachers were present in both groups. Participants may have felt uncomfortable expressing views that contradicted the group or the headteacher. To remedy this limitation, the researcher bought up opposing views as well as including the benefits and risks to balance the discussion. Interviews may have been a way to discuss participants views on data sharing to minimise participants not feeling comfortable raising opposing views to their colleagues or managers; however, individual interviews raise their own limitations.

5.4.4. *Future Directions*

This chapter discussed the perceptions of teachers when thinking about sharing student health information. Teachers were able to come up with an information-sharing system that maximised the benefits, managed the risks and made the transition between home and school (and parents and teachers), more accessible. However, little detail was given to what information should not be shared, whether all types of health information should be shared, and who should be able to access it. It is essential to also include the other key stakeholder, parents, in the conversation as it directly affects them, their child and their whānau, without having their teacher-hat on concurrently. The following chapter will delve into the beliefs of parents and ask them their thoughts about a DSHISS and the integration of health in schools.

Chapter Six Phase 3: Parent Perceptions

Fundamental in data-sharing of primary school children are the views of their parents and whānau. Including parents in the discussion incorporates a critical element of the school community and allows parents to have a voice in the development and implementation of a DSHISS. This inclusion of parents enables parents to discuss their concerns and work collaboratively with educators. The collaboration from this approach strengthens the relationships between schools and parents and helps build trust in the education system.

Phase 3 followed the same procedure as Phase 2, with participants invited to complete a questionnaire (Phase 3A) and invited to participate in a follow-up focus group where they could expand on their views and discuss important factors of a DSHISS.

6.1. Aims

This chapter aims to build on phase one and two findings by capturing the attitudes towards DSHISS from parents from three Canterbury schools. Phase 3 expands the study by including a more detailed questionnaire for parents than in phase 1. Phase 3 also utilises focus group discussion to allow participants to analyse their own and others' views.

6.2. Phase 3A – Parent Questionnaire

6.2.1. *Methods*

Participants

Participants must have been a parent or caregiver of a student in year 0-2 at School A, B or C to be eligible for the research. A total of 291 parents or caregivers were eligible to participate in this study.

Questionnaire Development

For consistency, the development of the parent's questionnaire along with the consent form and information sheet (see Appendix E.1) occurred alongside the kaiako questionnaire from phase 2A. Phase 2A describes the development of these questionnaires (refer to 5.3.1 Method).

Screening questions were placed at the front of the questionnaire. If participants were completing the questionnaire via electronic format (QualtricsTM), and they did not meet the inclusion criteria, they were thanked for their time and the questionnaire terminated. Paper formats also informed parent participants that if they did not have a child in year 0-2 ("…*unfortunately at this time, we are only looking at discussing the topic with parents of new entrants' students. Thank you for understanding*"). The final parent questionnaire consisted of two screening questions (asking whether their child is in year 0-2, and which school does your child go to), 12 main questions, and five demographic questions (see Appendix E.1). Similar to the kaiako questionnaire in phase 2A, most questions allowed for tick box answers, while still leaving an '*Other'* option for participants to expand on their views and provide qualitative data for thematic analysis. The kaiako and parent questionnaires were explicitly designed to mirror each other, asking the same question wording that reflected their role as a parent or teacher. For example, the teacher questionnaire asked "*what concerns do you <u>as a teacher</u> have with being able to access your student's health information?*", while the parent questionnaire asked, "*what concerns do <u>you as a parent</u> have with sharing your child's health information with their teacher?"*. Demographic questions followed the kaiako questionnaire in the most part, with only two items removed (*role at school* and *number of years working as a teacher*) and replaced what their highest education qualification was and the relationship to the child (e.g. *mother, father, foster parent*).

Procedure

Due to the different natures of the schools involved, personalised approaches to data collection were employed to fit the school, the parents and the community best. Individualised approaches were based on feedback from the headteachers at each school on how best to engage with parents. At all schools, this meant taking a multi-faceted approach, relying on several methods, both technological and physical, to gain traction and trust with parents. At School A, a three-pronged approach was employed to engage with parents. First, the researcher was present multiple days at School A for drop off (8.20-9 am) and pick up (2.15-3 pm) times, introducing herself to parents and their children and discussing the questionnaire. Parents were offered to take the questionnaire home and post it back via a prepaid envelope, or to fill it out at the time. Older students at School A (year 11-13) also assisted in this process, helping with whānau who struggled with English, reading or writing. The second approach involved putting an article in School A's online newsletter with a link to the online questionnaire (see Appendix E.2). The final approach utilised School A's shared Wi-Fi initiative, where eligible parents were asked to complete the survey by email through this shared Wi-Fi.

Similar approaches occurred at School B and C. In School B, the face-to-face engagement with parents was done by the researcher after school. This engagement was due to suggestions by the teachers that drop off's in the morning would be ineffective with parents needing to get to work or drop other children off. Three approaches via technology were undertaken. Similar to School A, an article was placed into School B's online newsletter, and a message posted onto School B's Facebook page was also uploaded. The headteacher of the year 0-2s at School B also sent an email to all eligible parents about the study. All of these approaches included a direct link to the online questionnaire via Qualtrics. Unfortunately, a terrorist attack conducted on March 15, 2019, in Christchurch meant that data collection ended prematurely. During data collection, on March 15,

2019, a lone gunman killed 42 individuals at the Al Noor Mosque and a further seven at the Linwood Islamic Centre (Bayer & Leask, 2020). Two additional people died in hospital after the attack with a further 49 injured across the two mosques. Victims were aged between 3 – 77 years old. This attack had a significant impact on the well-being of Muslim whānau. Data collection ended prematurely to in respect of the level of trauma many families were experiencing and the impact on others in the region. The decision to end data collection was made in conjunction with the headteacher. The event caused significant stress for both students and school staff who were placed into lockdown until the terrorist was in police custody. As a result of the premature end of data collection, response rates remained low.

Data collection for School C began at the beginning of term two and lasted ten weeks. Over this time, the researcher made multiple visits (once or twice a week) to School C when parents were dropping off their children (similar to the method in School's A and B). The researcher would introduce herself, what the purpose of the study was, and how parents could participate. Some parents were able to complete the survey before they left. Others took the questionnaire home and returned it to their teachers. Secondly, all teachers emailed out the online version of the questionnaire and put a small amount of information, along with a link to the online questionnaire, in their junior school newsletter. Finally, all children took home a hardcopy questionnaire along with an information sheet, consent form and prepaid, addressed envelope.

Data Analysis

As discussed in chapter 3.4 and similar to the data analysis in phase 2A, phase 3A utilised multiple statistical tests to analyse quantitative data. An ANOVA was used to find the differences in

participants ages by school. FET was employed to measure differences between schools and analyse differences by School for the Likert scale.

As discussed in chapter 3.4, a shortened version of thematic analysis was undertaken in phase 3B. The majority of comments within the parent's perception questionnaire were able to be placed into themes developed in chapter four. For inter-rater reliability, another researcher looked over the themes, scrutinising the comments and codes in each theme, with 100% agreement without any further discussion required.

6.2.2. *Findings*

Response Rates

A total of 99 (34%) questionnaires were completed, with 45 (45%) done through the online platform, Qualtrics, and 54 (55%) supplying the hardcopy questionnaire. The response rates of parents differed between schools, with School A obtaining the highest response rate of 71%. In comparison, School B and C had lower response rates (25% and 30%, respectively).

Demographics

Participants were mostly NZ European, female and ranged in age from their late twenties to late sixties. Most participants were mothers of a child at School A, B or C (see Table 6.1). Three significant differences existed between schools. Participants from School A (36.9 years) were significantly younger than School C (42.0 years; $p = 0.03$), had a higher Māori population and had a range of different qualifications. School B had a higher population of Asian participants and, along with School C, had a higher number of participants with post-secondary education.

Table 6.1

Demographic information of parent participants

Characteristic	School						Total		p-value
	A		B		C				
	n	%	n	%	n	%	n	%	
Gender [a]									
Male	4	13	6	17	3	9	13	13	0.66
Female	27	87	29	83	29	91	85	87	
Ethnicity [ab]									
NZ European	22	71	20	57	27	84	69	70	0.05
Maori	12	39	2	6	1	3	15	16	< 0.01
Pasifika	2	7	0	0	1	3	3	3	0.20
Asian	1	3	8	23	2	6	11	11	0.04
Other	0	0	5	14	2	6	7	7	0.08
Prefer not to say	0	0	1	3	1	3	2	2	
Education [a]									
None	10	32	1	3	0	0	11	11	
Secondary	9	29	1	3	2	6	12	13	< 0.01
Post-Secondary	7	23	32	91	28	88	67	68	
Prefer not to say	5	16	1	3	2	6	8	8	
Caregiver Role [c]									
Mother	25	81	28	83	28	88	78	81	0.82
Father	4	13	5	14	3	9	12	13	
Other whānau	2	6	0	0	1	3	5	5	

Note: [a] 1 value missing (1%); [b] Multiple responses possible; [c] 3 values missing (3%)

Teacher Access, Teacher Awareness and Consent

The majority of participants were positive towards the idea of sharing student health information with teachers. Overall, 90 (91%) parents recognised that health information was beneficial for teachers to be aware of, and 72 (73%) believed teachers should have access to their students' health information. There was no difference in the participant attitudes about teacher access to health information or teacher awareness of health information between Schools ($p = 0.36$ and $p = 0.99$, respectively; see Table 6.2). In terms of how to consent to student health information-sharing,

participants were only slightly in favour of having a request made separately to enrolment (60%; see Table 6.2). No significant differences existed between Schools (FET, $p < 0.05$).

Types of Health Information and Different School Staff Members

Participants considered what information should be shared with teachers. Hearing and vision, life-threatening illness and ongoing or chronic conditions had the highest majority believing they should be shared (see Table 6.2). Further analysis comparing schools found School A differing significantly from School B and C on whether re-occurring illnesses and all medical information should be shared. School A had higher proportions of participants believing re-occurring illness (77%) and all medical health information (53%) should be shared with teachers or schools than School B or C (43% and 53% respectively, FET, $p = 0.01$; 20% and 25% respectively, FET, $p = 0.01$).

Participants were happier for teachers who were directly involved with their child (classroom teacher) and health staff to access student health information (75% and 71%, respectively). Only three participants (3%) believed none of the outlined school staff should access student health information. No differences were found in beliefs on who should access student health information across schools (FET, $p > 0.05$; see Table 6.2).

A Parent's Role in Health and Health Information-sharing

When asked about the role of the parent, participants saw parents having various roles. Over 75% thought to discuss the relevant health concerns of their children with teachers and providing consent were some of the roles of parents. In comparison, only a small number (15%) thought that their role is to keep health information between the doctor and the whānau (see Table 6.3). More participants from School C thought that one role of the parent was to ensure their child does not put other

Table 6.2

Findings of Parent Questionnaire by Question

Questions asked and answers given	Overall		School						FET p-value
			A		B		C		
	n	%	n	%	n	%	n	%	
Do you think that a teacher should have access to a child's medical/health records? [a]	72	73	26	82	23	67	23	72	0.36
Do you think that teacher awareness about a child's medical/health information is important to the teaching and learning that happens at school? [a]	90	91	29	91	32	91	29	91	0.99
Consent to student health information should be:									
automatically given	40	40	16	50	13	37	11	34	0.43
Given with request	59	60	16	50	22	63	21	66	
What information should be shared with teachers? [a]									
Hearing and Vision	88	89	30	94	32	91	26	81	0.31
Life threatening illness	83	84	27	84	29	83	27	84	0.99
Ongoing or chronic illness	80	81	27	84	26	74	27	84	0.54
Immunisations	73	74	25	78	22	63	26	81	0.18
Mental Health	70	71	23	72	23	66	24	75	0.68
Recurring Illness	59	60	27	84	15	43	17	53	0.01*
Oral Health	52	53	22	69	16	46	14	44	0.09
All medical information	32	32	17	53	7	20	8	25	0.01*

None	2	2	0	0	1	3	1	3	0.99
Who should have access to student health information? [a]									
Classroom Teacher	74	75	22	69	28	80	24	75	0.57
Health Staff	70	71	22	69	26	74	22	69	0.89
Principal	52	53	14	44	22	63	16	50	0.30
Senior Management Staff	45	45	14	44	17	49	14	44	0.91
Support Staff	41	41	17	53	12	34	12	38	0.26
Teachers in Year Group	28	28	12	38	9	26	7	22	0.40
None	3	3	2	6	0	0	1	3	0.31

Note: * denotes significant p-value ($p < 0.05$)

[a] Reflects the number and percentage answering “yes” to this question.

children at school at risk of infectious illness (91%) compared to School A (56%) and School B (67%; FET, $p < 0.01$). Responses to all other questions did not differ between schools. Five comments with this portion of the questionnaire highlighted the need to protect privacy, share health information if the health concern was impacting learning and be in control of the child's information.

A Teacher's Role in Health and Health Information-sharing

Participants discussed reactive safety, ensuring privacy and providing holistic support were leading roles of the teacher (79%, 70%, 69% respectively; see Table 6.3). Only a small number of participants believed teachers were to take on a parental role during school hours (19%). School A had a lower proportion of participants believed a teacher's role was to make classroom adjustments based on student health concerns (FET, $p = 0.01$). School C believing that teachers need to act on the parents' behalf more than participants form School A and B (FET, $p < 0.01$).

A School's Role in Health and Health Information-sharing

The majority of participants believed that all five given options were the role of the school (see Table 6.3). The schools' role to provide a safe environment for students (85%) and inform teachers of student health information that could affect learning and behaviour at school (85%) had the highest agreement. School B and C participants believed the role of the school was to ensure the school environment fosters learning significantly more than School A (FET, $p < 0.01$). No other differences were found between schools. Participants indicated they had several concerns with sharing student health information with schools and teachers, none of which differed by School (FET, $p > 0.05$). Over half of participants had concerns with the information shared being too sensitive (60%), that labelling (60%) or discrimination of both the student and whānau (56%) was a risk and that parents would be unable to control what information was shared (54%; see Table 6.3).

Table 6.3

The role of parents, teachers and schools in managing student health

Roles	Overall		School						FET p-value
			A		B		C		
	n	%	n	%	n	%	n	%	
Parent role [a]									
To ensure teachers have relevant health information regarding students with health concerns	76	77	23	72	25	71	28	28	0.23
To allow teachers access to health information that could concern the child's learning	74	75	22	69	25	71	27	84	0.31
To provide teachers with relevant health information	71	72	23	72	23	66	25	78	0.50
To ensure their child does not put other children at school at risk of infectious illness	67	68	18	56	20	57	29	83	0.01
To allow teachers access to health information that could concern the safety of others at school	64	65	21	66	18	51	25	78	0.08
To give consent for access to health information	57	58	16	50	21	60	20	62	0.62
To limit who can access their child's health information	38	38	7	22	16	46	15	47	0.07
To keep a child's health information between the whānau and the doctor	15	15	7	22	2	6	2	6	0.13
Teacher role [a]									
To know how to act in a medical incident	78	79	22	69	28	80	28	87	0.21
To ensure a students' private information is only shared with individuals on a need to know basis	69	70	21	66	23	66	25	78	0.48
To provide emotional and social support when required	68	69	20	62	24	68	24	75	0.52
To understand students' health backgrounds	64	65	22	69	22	63	20	62	0.89
To adjust teaching according to students' health background	64	65	14	44	26	74	24	75	0.01
To be fully aware of any student health concerns	60	61	21	66	17	48	22	69	0.19

To act on the parents' behalf when necessary	60	61	15	47	18	51	26	81	0.01
To educate students with what health information is available to them	39	39	14	44	10	28	15	47	0.52
To discuss student health concerns with parents prior to providing support or teaching adjustments	36	36	8	25	13	37	15	47	0.19
To take on the role of a parent during school hours	19	19	7	22	4	11	8	25	0.37
School role [a]									
To provide a safe environment for students	84	85	26	81	29	83	29	91	0.60
To ensure teachers are well informed of health information that could affect learning and behaviour at school	80	81	25	78	28	80	27	84	0.81
To minimise infectious illness	70	71	19	59	24	68	27	84	0.07
To ensure the school environment fosters learning	67	68	15	47	25	71	27	84	0.01
To ensure parents are well informed of what sensitive information has been passed on to teachers	63	64	17	53	22	63	24	75	0.19

[a] Reflects the number and percentage answering "yes".

Participants indicated they had several concerns with sharing student health information with schools and teachers, none of which differed by School (FET, $p > 0.05$). Over half of participants had concerns with the information shared being too sensitive (60%), that labelling (60%) or discrimination of both the student and whānau (56%) was a risk and that parents would be unable to control what information was shared (54%; see Table 6.3).

Perceived Concerns and Benefits

The sensitive nature of health records and the labelling of students and whānau were concerns for 60% of participants (see Table 6.4). Concerns with discrimination (56%), lack of parental control of what information is shared (54%) and whom the information is shared with (54%) were perceived as risks if student health information was shared. No significant differences were found when comparing participant answers between Schools.

Over 55% of participants saw there were several benefits in sharing student health information. These included the ability for teachers to consider health concerns and adjust their teaching if necessary (79%), act in a health incident (79%), holistically support students (72%) and assist teachers understanding of any learning concerns (59%). Other benefits had a smaller proportion of agreement from participants (see Table 6.4). No significant difference between schools was identified (FET, $p < 0.01$).

Participants were asked near the end of the questionnaire where they sat on a simple 5-point Likert scale asking their level of agreement with the statement “the benefits of sharing health information with teachers outweighs the risk”. The analysis showed a slight agreement ($M = 3.56$, S.D. = 1.09)

Table 6.4

Parent's perceived concerns and benefits of sharing student health information with schools and teachers

Perceived concerns and benefits	Overall		School						FET p-value
			A		B		C		
	n	%	n	%	n	%	n	%	
Perceived concerns [a]									
Some medical record information is sensitive/don't want all the information to be shared	59	60	15	47	23	68	21	66	0.24
Labelling the student or whānau based on a diagnosis in their medical records	59	60	16	50	23	68	20	62	0.40
Discrimination/disadvantaging the student	55	56	21	66	20	57	14	44	0.23
Parent can't control what information is shared	53	54	12	37	19	54	22	69	0.05
Parent cannot control who sees their child's health information	53	54	13	41	20	57	20	62	0.82
Unfairness if information has been shared but parent unable to access the information themselves	45	46	15	47	17	48	13	41	0.20
Teachers not trained to handle or access health information	21	21	5	16	9	26	7	22	0.62
This information is *tapu* and needs to be respected	19	19	10	31	3	9	6	19	0.09
Perceived benefits [a]									
Teacher can adjust teaching to consider health concerns	78	79	23	72	30	86	25	78	0.39
Teacher will know what to do in a health incident	78	79	23	72	29	83	26	81	0.56
Teacher are to support the whole child, physically and emotionally	71	72	20	62	28	80	23	72	0.28
Helps explain learning concerns	68	69	17	53	26	74	25	78	0.08

Able to ensure infectious illness is managed at school	58	59	17	53	20	57	21	66	0.62
Gives teachers immediate information when/if needed	52	53	18	56	13	37	21	66	0.06
Teacher able to prevent child from getting unwell	34	34	11	34	13	37	10	31	0.96
Teacher will understand child's health background	29	29	26	81	23	66	21	66	0.30

[a] Reflects the number and percentage answering "yes".

where "*strongly disagree*" was assigned as one through to "*strongly agree*" assigned as five. No significant differences between school were identified (see Table 6.5).

Table 6.5

Parent perception of benefit vs. risk in sharing student health information

Do the benefits outweigh the risks of sharing student health information?	Total		School						FET p-value
			A		B		C		
	n	%	n	%	n	%	n	%	
Frequency									
Strongly Disagree	5	5	3	10	1	3	1	3	p = 0.31
Disagree	15	15	1	3	8	23	6	19	
Neither Agree or Disagree	14	14	5	16	5	14	4	13	
Agree	48	49	15	48	18	51	15	47	
Strongly Agree	16	16	7	23	3	9	6	19	

Thematic analysis of participant explanations and comments

Seventy-seven (78%) participants made 244 comments. Twenty-three comments (9%) were discarded as they were unable to be analysed (e.g. "Yes"). Inter-rater reliability was completed on the remaining 221 questions. Seven comments (3%) were discussed with another researcher due to disagreement on which theme the comments best fit. Five of these comments were discussed and incorporated into other existing themes, with the researchers agreeing the other two comments best fit in their original theme. As a result, 100% inter-consistency was reached.

Thematic analysis of 221 comments and explanations was undertaken, covering each section of the questionnaire. Five key themes were identified (*teacher awareness*, *limitations needed*, *inclusion of parents*, *safety* and the *role of the teacher*). All four themes were previously identified in phase 1 and 2 and were consistent across the questionnaire (see Figure 5.1 located in the previous chapter). The consistency between these findings themes is understandable due to the similarities between the

questionnaires used in phase 2A and 3A. The *teacher awareness*, *limitations needed* and *the inclusion of parents* themes were the main focus (67, 29 and 26 mentions respectively). Of these 221 comments, 121 (55%) comments were discussed by 72 participants (73%) were explanations from the teacher access and teacher awareness questions.

Teacher awareness

Within the *teacher awareness* theme, participants discussed the potential benefits that sharing student health information could have on either practical support for learning and holistic well-being. The theme was identified in the teacher access and teacher awareness questions, along with questions that discussed what health information should be shared, the role of the teacher, and in the final comments section. The *practical support* subtheme considered how teachers can provide an active role in supporting learning, demonstrating an understanding from participants of the impact of health on education ("*some medical issues will affect the child's ability to learn, and the more the teacher knows about the child then they can understand their needs and teach them accordingly" – Participant 2114*). The *holistic well-being* subtheme considered teachers providing support for factors outside academic learning ("*for teachers to be able to meet emotional, social, all health issues and be (helped to meet) aware of child's background" – Participant 2171*)

Limitations needed

Comments regarding the limitations needed theme was incorporated throughout the questionnaire. Similar to phase 1 and 2A, this theme encapsulated many of the "buts" or "only if" in the teacher awareness and teacher access questions which required participants to give binary yes/no answers. This theme picked up on the grey area between these binary answers, where specific information may or may not be shared based on the nature of the data and why the data is being used. The theme

was better explained with the incorporation of two sub-themes. The first explains that limitations on what information is shared were based on the data is relevant to day-to-day safety or learning ("*not unless it directly relates to their learning or is something that is a safety issue i.e. allergies" – Participant 3150*). The second subtheme discussed limiting who would be able to access shared student health information. For participants, access centred around giving information only to those who needed it (*"teacher in year and support staff if relevant" – Participant 3100*).

Inclusion of parents

Participant comments discussed the need for parent inclusion and the potential for harm. They questioned whether accessing information was a teacher's role. The *inclusion of parents* theme highlighted the need for conversations with parents and whether, as a consequence of digital health information-sharing, this conversation would be lost:

> *"That the natural process of a parent-teacher conversation will no longer be needed. That perspective will be lost. That relationships between those educating my child and myself are no longer able to be built because they will have a lot of information at the click of a mouse" – Participant 1010*

This theme (*inclusion of parents*) was split into two subthemes, *direct discussion* (with parents) and *parental responsibility.* The *direct discussion* subtheme centred on including parent and teachers in the conversation on what and why information is shared. The *parental responsibility* subtheme highlighted the responsibility in sharing information and providing consent. A parent's responsibility concerning health information-sharing is to act as a gatekeeper, sharing "*...at the parent's discretion" (Participant 2169)*, "*…on a consent basis by the parent*" *(Participant 2128)*. The theme considers the importance of relationship-building between teachers and parents:

"Most definitely however the information should be shared in a way with teachers, so that it can be discussed together and explained so there any plans can be co-designed between teachers and parents" – Participant 1098

Safety

The *safety* theme covered both preventative and reactive safety, whereby schools could make adjustments that keep children safe and react if needed to medical incidents when they were aware of health information:

"In case there is an emergency" – Participant 1099

The *safety* theme is a potential benefit of sharing student health information. It may help teachers and school prevent medical events occurring (in the case of allergies for example) and ensure teachers and schools are prepared to act if necessary, in the event of a medical incident due to a known health concern.

Role of the teacher

The *role of the teacher* theme incorporated many of the already identified themes in this chapter. This theme discussed the differing roles and expectation teachers have in providing a safe environment, that fosters learning and well-being:

"As children spend a lot of time at school out of parental care, teachers need to be informed of any issues they may have to manage during the day, i.e. allergies, illnesses, medicine that needs to be administered" – Participant 2111

Participants raised concerns about how teachers can often be expected to fill other roles at the expense of their teaching role, despite the lack of training in these roles ("*teachers can't be expected*

to be a social worker, doctor or parent with such big class sizes, but they do need access to relevant information to teach child well" – Participant 2197).

Phenomena not discussed in phase one

Similar to phase 2A, ten comments discussed phenomena that were not included in one of the themes in phase one. One of the phenomena discussed the need to ensure that if teachers were to access student health information, they would require efficient resourcing:

> *"… more specificity on the context and outcomes sought (learning, disease control etc) will likely give different answers …. It's always better to share information if used in the right way, and where there is a capability and readiness to use it for the intended outcomes… I don't think schools are there…" – Participant 3149*

The other phenomena discussed were solutions to how consent could be given and displays genuine interest from participants on how a DSHISS may work. Participants considered both opt-in and opt-out methods while considering the ability for teachers and parents to works together:

> *"if included in enrolment would have to be very clear. "Opt in" as required would be better" – Participant 2203*

> *"Most definitely however the information should be shared in a way with teachers, so that it can be discussed together and explained so there any plans can be codesigned between teachers and parents" – Participant 1098*

6.2.3. *Implications for phase 3B – focus group interview schedule creation*

This phase of the research project helped guide the development of the focus group interview schedule for the next phase (phase 3B). The parent's questionnaire helped expand certain areas to be discussed, such as thinking about resourcing, pragmatic solutions to foreseen risks, and what a DHISS could look like if implemented. With these results and the interview schedule from phase 2B, a similar interview schedule was developed (see Appendix E.3). Participants also discussed the "only if..." idea that in sharing health information would be situational, and thus examples of fictitious children were created where teachers may want to access health information if it was available. These examples were utilised to help parents who were to participate in the focus group to consider what the benefits or risks could be and provide a discussion point if needed.

6.3. Phase 3B – Focus Group Interviews

Participants were invited to one focus group held at each corresponding school. Focus groups allowed participants to explain their reasoning and experiences better while having a conversation on how they feel about a student health information-sharing system with a group who may have differing views from them. Phase 3B aims to utilise the findings of phase 3A and allow participants to discuss their beliefs in more depth.

6.3.1. *Methods*

Participants

As in phase two, participants who were interested in phase 3B were identified through phase 3A, where the questionnaire asked participants whether they would like to be involved in a follow-up focus group. Of those 99 who completed the survey, 41 (41%) indicated they would be interested were contacted via email or phone with a time to meet.

Interview Structure Development

Interviews followed a semi-structured approach and addressed themes identified through the respective questionnaires in phase one. The interview structure followed the teachers focus group interview structure to keep a similar delivery between teacher and parent participants. The parents focus group did change slightly, with examples introduced to help participants engage in more discussion with each other in the beginning. The interviewer made suggestions from previous focus groups if the participants had bought up similar views and comments. These suggestions helped build more considerable discussion and expand the ideas discussed. Similar to the teachers' interview schedule, the parents' interview schedule covered five main parts, the benefits and risks of sharing student health information and the roles of teachers, parents and school (see Appendix E.3). Similar to phase 2B, probes and keywords were utilised when and if necessary, to stimulate conversation in particular areas or expand on discussion points.

Procedure

Three focus groups were held for participants from each school. The researcher provided each focus group with a small platter of kai and had a general conversation to help ease any nervousness the participants may be feeling. Two voice recorders were used to record the conversations. Before the audio recording began, participants were asked to read through the information sheet and sign a consent form (see Appendix E.3). Participants chose a pseudonym to for the write up of their focus group, with one female participant choosing the pseudonym Bob. The researcher gave a short description of privacy and confidentiality to ensure the participants were clear about the expectations to keep each other's views protected. Once they had selected a pseudonym, the recording began, verbal consent asked for with the pseudonym names and the interview schedule followed.

Both focus groups followed an interview guide. This guide helped structure the interviews and provided the focus group five points for discussion which cover risks and benefits of student health information sharing and the roles of parents, teachers and schools. At the end of the focus group, each participant was able to add any closing remarks, ask questions to the group or summarise their thoughts. The recording was ended, and participants thanked and given a small koha to show the researcher's appreciation for their participation and time. Consolidated criteria for reporting qualitative studies by Booth et al. (2014) were utilised in the write up of phase 3B.

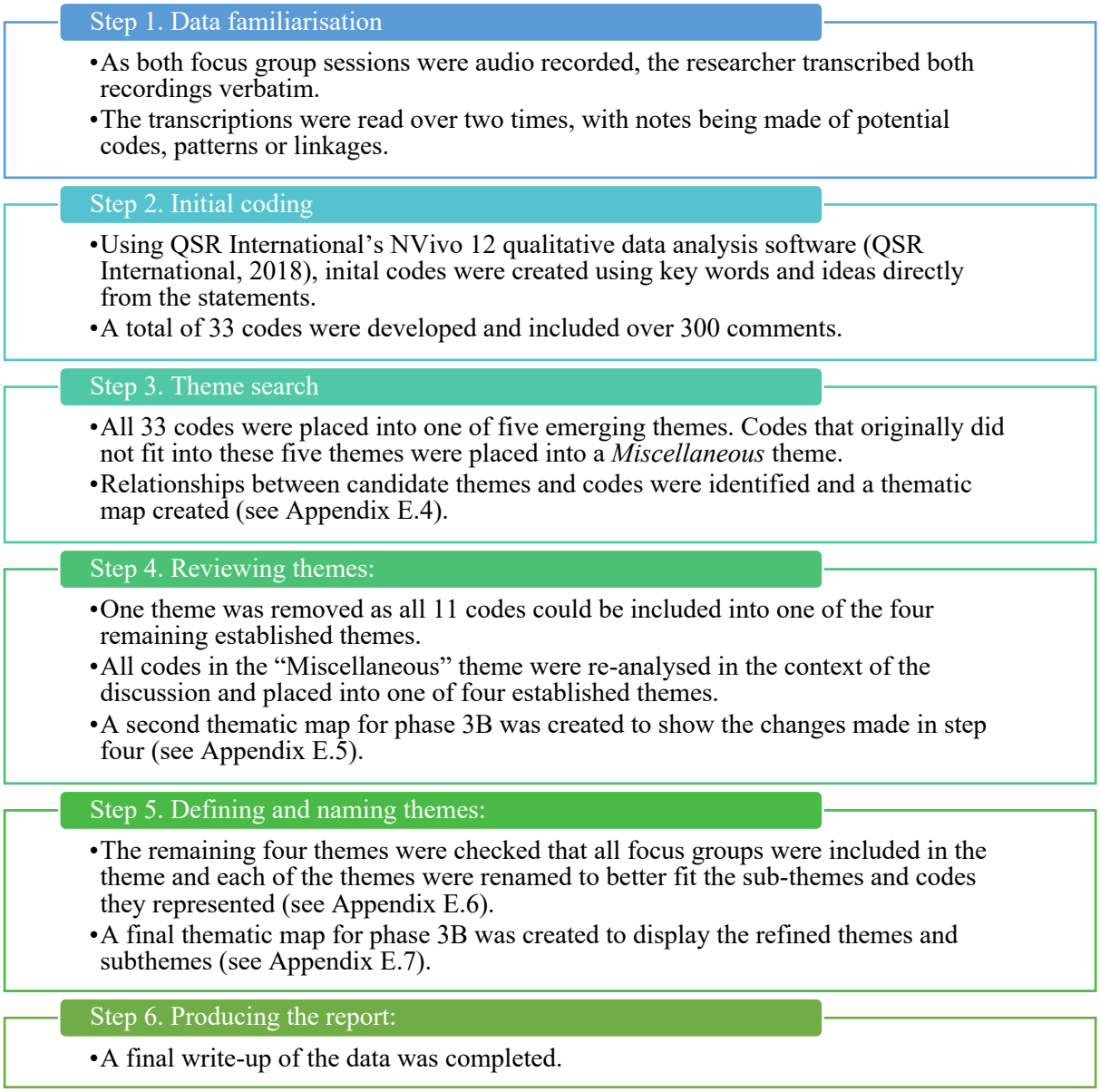
The focus group for School A was held at 1400 hours, 30 minutes before school ends. School B held theirs at 0900 hours, 15 minutes after School Began. Both School A and B focus groups were held at their respective schools to minimise barriers in attendance to the focus groups. School C was held at 1830 hours at the University of Canterbury. The decision to have the focus group at the University of Canterbury was made due to the lateness of the meeting, and not wanting a teacher to have to stay at work later just for parents to attend a focus group at school. The researcher discussed this with participants and gave clear instructions for participants on where to park and where the focus group would be held. Each interview lasted between 40 and 55 minutes each.

Data Analysis

Utilising the techniques described in chapter 3.4, six steps to thematic analysis as per Braun and Clarke (2006) were utilised to analyse data from parent focus groups. Figure 6.1 shows the process undertaken for this qualitative analysis.

Figure 6.1

Process of thematic analysis for phase 3B



6.3.2. *Findings*

Forty-one participants across the three schools from phase 3A were invited to participate. Of the 41, 7 (17%) declined, 19 (46%) did not reply, and 5 (12%) were unable to make the timing. The remaining ten parents were able to make the focus group and participate (24%).

Participants were all female and identified as NZ European (80%), Māori (20%; one participant identified as NZ European and Māori) or Other Ethnicity (10%). Participant ages ranged from 33 years to 58 years (M = 42 years, SD: 8.22) and did not differ between schools ($F(2,6) = 0.23$, $p = 0.80$). The majority of participants from School B and C had post-secondary qualification (100% and 67% respectively), which differed significantly from School A (0%; FET, $p < 0.05$). No other significant differences between participants from the three schools were found ($p > 0.05$).

Thematic analysis of focus groups

The analysis found four themes covering 12 subthemes, all of which carried through the three focus groups (see Figure 6.2). Participants critically discussed the DSHISS, with some participants disagreeing with others. This disagreement highlighted the polarising material the focus groups did contain, with examples given that showed potentially inequitable experiences within both the health and education systems within New Zealand. Despite the conflict, participants were able to discuss amicably and respected others experiences as valid.

Theme One – Acknowledging the different roles within Education

Each individual who engages with schools has varying roles, with many of these roles overlapping depending on the circumstance and the community. This analysis found four separate roles in the education system, the role of the teacher, school, parent and GP. Participants viewed each of these roles as continuously evolving to suit the needs of the student, and thus determining each role (and the individual who carries out that role) requires a level of flexibility.

Figure 6.2

Parent's beliefs toward health information sharing - themes and sub-themes

Theme One: Acknowledging the different roles within Education

- The role of the teacher
- The role of the parent
- The role of the school
- The role of the GP
- Need for flexibility

Theme Two: The benefits of sharing information and the losses if we don't share

- The ability for educators to provide tailored holistic support for learning and well-being
- Improved day-to-day safety

Theme Three – The potential for harm

- Dangers of how health information could be interpreted or misused
- Adding to an over-burdened and under-resourced sector

Theme Four: Solution-focused Implementation

- Justified access and the development of a traffic light DSHISS
- Need for clear policies and guidelines
- Prioritise empowering relationships with whānau

The role of the teacher

Participants believe that a teacher's role includes to teach academic skills, provide a safe environment for students and provide pastoral care (Teaching Council New Zealand, 2017). Teachers are often better able to pick up on health and development concerns than parents due to the time they spend with the students. The complexity of the teacher's role has grown, especially as the understanding of how biopsychosocial factors can impact students in the classroom. They are expected to provide support to students and their whānau, teach social and self-regulation skills and be aware of life-threatening health conditions. Teachers can influence the classroom environment when they are aware of their student's health. They may make adjustments or get extra resourcing to support children's health needs or create safe environments for those students with allergies. They often provide emotional support, particularly for new students or students who are dealing with changes at home:

"… my child, last year, in particular, was having, real sadness when his dad was travelling… I really relied on the teacher to, who I talk to about it because I have a relationship with her, to just support him through the first 10 or 15 minutes of every day when I was leaving…" – Jax (School C)

There were concerns, however, that sharing student health information may impact teachers negatively. Participants raised the concern of whether by providing all this holistic support whether teachers are taken away from teaching students curriculum content:

"it's taking away from teachers teaching your child to do maths, writing and reading… you don't want your classroom teacher who are already maxed out, having any extra" – Jax (School C)

Participants questioned teachers' scope of knowledge and whether teachers are equipped to handle this shared health information appropriately, or if they should even be expected of them to know how to handle it. Concerns raised included the idea of "…*they're not a healthcare provider…" (Bob – School A)* and how teachers cannot be expected to become one if this information was shared.

The role of the parent

Not surprisingly, all participants believed that consent was a parental role. Whether consent is given automatically, or with a separate request, parents "*…act on behalf of…*" *(Jax – School C)* the student and ultimately have the final say on the release and access their child's health information. Participants discussed how the role of parents has changed, partly due to the increasingly busy lives parents have. Toothbrushing in schools was given as an example highlighting how parents were unable to find time or motivation to brush their child's teeth in the morning, resulting in an opportunity for schools to fill this role.

The role of the school

The role of the school concentrated around two main features; 1) the need to provide a safe environment and 2) their role in providing for their community. Schools have a responsibility to be safe spaces for students. The safety may be preventative, where they ensure equipment is safe or dangerous areas either blocked off or monitored, and can either begin to incorporate the idea of preventing the spread of infectious illness through immunisation statistics or disease management:

> *"... if schools knew [about vaccinations], they wouldn't specifically need to know if a child had, but as a wider community there is a percentage of students, say 3% of the school was not immunised. Not necessarily singling out individual children but you know, but there is a percentage that could potentially affect the wider school should there be an outbreak" – Holly (School B).*

The school role of safety can also be reactive, in that it has systems in place that handle the health of the students if needed. For example, supporting the administration of medication, having plans for medical emergencies (when health issues that have been raised by the whānau prior) and having policies around infectious disease management. Schools are well-placed in communities with many already prioritising the needs of the community, offering community and health services or events:

> *"...the school... that took the proactive step of writing to all the children who hadn't been vaccinated... so they made it really accessible, and they had a great uptake, and lots of parents hadn't even realised that the kids weren't fully vaccinated... It's, it's like you say the whānau and community, all coming together in a really good way" – Red (School C)*

Schools that have contributed to the community and public health have responded to community need. This could see schools acting in a potential driver of successful public health policies.

The role of the GP

The family doctor would play a vital role in sharing health information. Their notes or diagnoses being shared with non-medical professionals means they may need to remove jargon and specific information to allow the sharing to commence. It can also be a more time-consuming experience for both doctors and patients. Participants raised concerns they have with trusting medical professionals with information telling experiences of disrespect:

> *"… I've had a specialist come through and talk about her and my daughter in the most terrible way like she was subhuman. I don't want those people to be looking at anything of hers and making judgement" – Ella (School A).*

This trust (or lack of) can act as a considerable barrier to whether parents were open to sharing health information with schools. If the parent disagrees with the information that has been written, felt that the information did not accurately reflect the health concern, or felt any disrespect from the professional writing the information, they would be less likely to share it.

Need for flexibility

Participants identified that each of the individual roles often intertwined with each other in practice. The current practice of parents working alongside teachers, school and other health or support services has created consistency between home and school:

> *"one of my girls, her teacher and I… we've both finished doing the same course, so we're on the same page. That helps tremendously. There's stuff going on during*

the day time for her then, she can just give me a heads up, and then I can take that home, and we can work on that there, and it can work the other way as well" – Ella (School A)

While teachers work intertwined with parents and school, participants recognised the flexibility of these roles, were teachers and schools may be required to provide extra emotional or physical support for specific periods due to an event:

"*but it does change over time, and it changes quite quickly too … after two or three or four months, when your child fits in with school, but you're still wanting that closeness to the teacher…"* – Red (School C)

Theme Two – The benefits of sharing information and the losses if we don't share

The benefits of sharing health information include safety, practical and holistic support. For children with ongoing or chronic health needs, a well-placed DSHISS could mean whānau are no longer burdened with disclosing the student's story with every educator they meet. It also allows staff to prepare for their students' needs before the student enters the classroom. This process is similar to the referral system within health, where information is shared between health professionals through a digital system. A DSHISS also acts as a safety net for children whose whānau have not shared information. It takes the onus off parents to regularly update teachers about any new health concerns:

"…you can imagine instances when potentially they aren't seeing them because they are really stressed, you know break up at home or things going bad, and the child's kind of suffering from it…" – Eve (School B)

The ability for educators to provide tailored holistic support for learning and well-being

A DSHISS would enable teachers and schools to provide a range of tailored support to both students and their whānau. The ability to provide practical support that assists students to overcome their health concerns would improve as teachers can access this information. This awareness allows teachers to be better prepared in the classroom, make adjustments to the classroom, whether it be for minor health concerns to children experiencing physical disability:

> *"…if you have a child who has access issues to the classroom then you obviously need to modify the classroom to make, you know [the classroom accessible]… but even at a lower level if you remove the allergens from your class, all those kinds of things, I suppose it's not just the teacher behaviour, it's modifying the environment"* – Jax (School C)

With shared health information, schools may be able to put measures in place that provide detailed guidance on how to support students to overcome their health concerns at school. These measures can be as straightforward as ensuring the classroom is accessible to students with a disability, through to complex health management plans. These management plans could be done collaboratively with GPs (who share the information), allowing educators to work collaboratively with health professionals and provide informed practical support that helps overcome barriers to school success and improve health management. Schools and teachers would also be able to provide more well-rounded support:

> *"…sharing means that there's a much more broader holistic perspective on the child and as you say the family's current conditions and how can we support that, and it might be information for the health system on how to reduce these things*

happening if we kind of concentrate on a more education perspective… It just opens up the boundaries so that we can actually do better…" – Eve (School B)

Improved day-to-day safety

One of the primary benefits parents could see coming from a DSHISS was an improvement in safety. Teachers and schools having greater and more up-to-date awareness of student health mean they are better able to provide preventative measures and react to medical emergencies:

"…definitely removing those immediate hazards that are to do with allergies or, or any other related reactions that they're likely to have I suppose would be the first thing that would happened, and maybe being able to modify the environment so as to not exacerbate, whatever condition the child might have" – Jax (School C)

Theme Three – The potential for harm

There are substantive risks involved with sharing any types of personal or health data, particularly around misuse and misinterpretation. Many participants were able to call upon negative experiences they had had or had heard of. These experiences had included inaction from teachers, where parents have disclosed health information and have not received any support:

"….I've asked for help for one of my daughters who struggles to make friends and she um, so she's got a lot of things that she can, you know, she needs help with, and I've asked for help and advice or help, and I'm still asking for help, and I'm still not getting it" – Mia (School A)

The impact of ongoing systemic racism has also created significant risks for those minorities or indigenous cultures who historically have suffered from systematic bias. It is especially important to consider the potential for disempowerment, particularly for Māori, where whānau feel as if they have less autonomy over the children health information due to a DSHISS:

"…as Māori, I don't feel safe in our [health or education] system… I mean if we are looking at empowering families, and parents and whānau ora, self-determination, then you can't be taking things away, you need to be building things up to be better conductors of information" – Ella (School A)

Concerns were raised around the potential for relationships between whānau and educators to disintegrate as teachers could get all their students' information through a DSHISS and the financial and time benefits become a higher priority than ensuring the system is genuinely benefiting children.

Dangers of how health information could be misinterpreted or misused

Misuse and misinterpretation of health information was a common subtheme discussed. Misinterpretation of information could occur, notably where the information that is shared is missing vital context or background information. Misinterpretation of a diagnosis and the resulting adjustments teachers may make could be detrimental, especially if the adjustment negatively impacts the student. Participants across schools considered the potential for misuse by labelling students and discriminating against students based on their information:

"…it can be not so beneficial in the areas where labels are put on [students] unnecessarily" – Mia (School A)

"… I would be worried about our children being, having negative consequences from being labelled" – Red (School C)

Eve (School B) discussed an example shows how a school could implement poorly designed, dangerous adjustments that singled out, judged and ostracised a child due to their health concerns:

> *"…In Greymouth where there was a child who had, I think he was autistic or something, and they put signs up around the school with a big cross through his face, saying don't let him leave the school or do this, and they had private meetings where he was really singled out as this really wild child, that's, for me, seems like that its really damaging to the child" - Eve, (School B)*

Not only did the school's action impact the child with autism, but it also had notable consequences on the child's whānau and thus, provides evidence of how a DSHISS could be dangerous.

Adding to an overburdened and under-resourced sector

Participants had concerns around resourcing, and the current lack of resourcing schools are currently facing. There was consensus across schools that teachers were already stretched and if health information were to be shared, they would not be adequately supported in making use of this information:

> *"…if there was 6 different children with 6 different requirements; it could be really hard for the teacher to instigate that without the right support" – Eve (School B)*

Theme Four – Solution-focused implementation

Participants across schools discussed solutions to concerns they had about sharing their child's health information with many focussing on how these concerns could be addressed. Participants highlighted the need for teachers to be adequately funded, resourced and supported. Without this resourcing, the

benefits of a DSHISS, no matter how well-thought-out, will be minimised, if not nullified completely. Participants highlighted the idea of teachers already being overextended:

> *"it's a resource thing…you don't want your classroom teacher, I don't want the teachers who are working with our kids now, who are already, you know, pretty much maxed out, having any extra [work]…" – Jax (School C)*

Additional resourcing or support would be a necessary component to implementing a DSHISS. This resourcing could come in a myriad of ways such as the need for adequate education for educators on health and illness to minimise misuse or misinterpretation.

While the potential of a DSHISS was discussed from GP's to educators, participants considered the potential for information to be shared bi-directionally, as participants saw teachers as being well-positioned to make observations about a child's health and well-being:

> *"Teachers spend more time with our children during the week than we do awake often, so I can see a lot of issues, but potentially they see things that we don't see, and they know things about our kids that we don't know" – Jax (School C)*

Participants also considered that age in which the child themselves should have the ability to consent, raising further questions around when children should be involved in the consent process, and at what age does parental consent become inadequate or even irrelevant:

> *"…the age of the child might be significant as well, a 13-year old might, at some point the child has to have their own ability to say no" (Red, School C)*

Justified access and the development of a traffic light DSHISS

Participants believed having limits on who could access a DSHISS and what information was included in this system would help alleviate some of their concerns and minimise perceived risk. The student's classroom teacher was the most accepted professional to access a DSHISS as they have the most direct relationship with students and whānau.

Participants displayed hesitance for principals having access to the information at first. However, with greater discussion, they believed that principals should have access for different reasons to the classroom teacher. A principal may be able to provide guidance or support to teachers and act as a facilitator if significant adjustments to the school environment or policy are needed based on the shared health information:

> *"Principals need to be the overarching owners…if something that is really serious that does need to go to the board, then that's the senior management person who has to make the call on whether it needs to go wider…" – Bob (School C)*

Participants also highlighted that who has access to the information depends on what information is accessible. Life-threatening information was an example participants saw as being mostly shared with staff. The acceptance of sharing life-threatening conditions is based on safety rather than learning or holistic well-being. Access to information "*that is potentially lifesaving for the child" (Holly, School B)* would include teachers and senior staff and could extend to reliever teachers, administration and support staff.

Participants noted that physical health concerns are harder to quantify as they often fall into different areas of sensitivity. There was a focus on sharing health information if it was pertinent to learning

and information that could affect other children in the school were also discussed as being appropriate to share:

"Physical health sure, because that can be passed on to other children…physical health is going to affect the rest of the class…" – Holly (School B)

Most participants thought that immunisation records were already mandatory to share, believing that the same protocols existed for schools as it did in early childhood centres (where immunisation certificates are required). Sharing other physical or more sensitive information, however, was met with higher apprehension from participants:

"… it's more tricky with like, mental health issues…" – Eve (School B)

Despite the sensitivity, there were acknowledgements from participants about the impact mental health can have on children, and how that may relate to learning. This finding centred on Christchurch children who may have experienced a range of trauma from a natural disaster (2010/2011 earthquakes in Canterbury) and terrorism (2019 Christchurch Mosque Attack):

"…there's a lot of evidence to support the fact that particularly anxiety levels, particularly in this region, have had quite a, quite an amazing impact on behaviour and learning at school, so I think it would be foolish, in fact I would see it as being the main function of a system like that, would be to address any of those anxiety issues that, that crop up." – Jax (School C)

Participants were able to brainstorm what a DSHISS could look like to help regulate what information is accessed and by whom. As a result, a tiered traffic light system was introduced:

"I think it should be a tiered approach. The School could say, if your child has a life-threatening illness that may require treatment, you must, as part of the

school's policy, that you must tell us that information, or share that information…" – Eve (School B)

Participants thought a collaborative approach would be necessary to ensure health information was shared appropriately within the traffic light DSHISS. Involving the GP in this implementation was emphasised with many seeing GPs as having a pivotal role in facilitating what information is accessed. Using their health expertise, GPs could work alongside whānau where health information is placed within the traffic light DSHISS, allowing parents to inform what is shared and what is not:

"… a group of people would need to get together and discuss as a collective what they thought… was appropriate and needed to be on there, and then that would be drafted up for agreement… a GP could draw the line, and say scabies is health-related…This is physical; this is not" – Holly (School B)

Need for clear policies and guidelines

The development of a DSHISS must focus on providing guidelines and policies for the systems use, management and user responsibilities. The establishment of guidelines for informed consent, access and use will help keep the information safe. These policies and guidelines demonstrate a DSHISS implementation that minimises risks, likely improving consent statistics as parent concerns are addressed. These policies may include full visibility on who can access the information, what they can see and how to make the use of health information as transparent as possible. Participants raised the need to ensure that the system was monitored, suggesting senior management act as watchdogs to ensure the system was secure and being used appropriately:

"… how the databases is used would be something that the Ministry of Education is saying that 'this is how it is [used]', and that there would be a delegated person

within the school, whose job it is to make sure the updates are made so that their security is up-to-date …" – Red (School C)

Prioritising empowering relationships with whānau

One vital component discussed in successful health information-sharing is the inclusion of the whānau. Participants were concerned that one of the consequences of a DSHISS would be the loss of parental inclusion and relationships between the teacher and parent not being valued ("… *I just think that, you're missing a really important link and that would be the families…" – Ella, School A*). Participants across all schools highlighted the need to establish good relationships with parents. The main reason for emphasising the need for relationship building is trust:

"…it [sharing student health information] does involve a lot of trust doesn't it, you'd want to feel like you, that that database is safe and that only the right people were accessing it, so there needs to be lots of communication around, that is, it would be hard if you had a teacher that you weren't trusting them…" – Bob (School C)

The inclusion of whānau is vital to building trusting relationships. Participants suggested setting up meetings so that parents have the opportunity to meet those involved with their child's schooling. It begins relationship building between the whānau and teachers, leading to smoother communication between the two parties. One of the benefits of communication is the ability for teachers and parents to work together and provide consistency between home and school ("*…working with us, I can make the job easier, but we have to work together…so we're both on the same page" – Ella, School A)*.

Participant perceptions emphasise the importance of creating relationships between parents and teachers regardless of a DSHISS was in place or not, as these relationships are essential for parents to disclose sensitive information. It highlights the parent and whānau role as caretakers, and the potential of this role to be shared with teachers if a strong relationship is formed. Once that relationship is fostered, parents can trust that teachers will also see themselves as caretakers of the child's mana and be more open to sharing information:

> *"... it took relationships; it took time for me to build relationships with all these professionals so that I didn't have to prove myself... relationships are everything for everyone in any circumstance..." – Ella (School A)*

6.4. Discussion

In an in-depth review of the findings from phase 3, the focus group (phase 3B) added significant detail to the questionnaire results (phase 3A). Similar themes identified in the questionnaire were carried through the focus groups due to the interview structure, allowing the themes to be developed in more detail. A new theme was also developed (*solution-focused implementation*) as participants began discussing how the risks could be minimised, and the full potential of a DSHISS reached. This section will provide a summary of key findings, discuss the integration of these findings between phase 3A and 3B (see Table 6.6), link these findings with current literature, and consider any phase 3 specific limitations.

6.4.1. *Establishing whānau perceived value in a DSHISS*

For parents and whānau to be open to sharing their child's health information, they must understand the value and benefits that result in such sharing. Participants discussed the benefits of a DSHISS in

Table 6.6

List of integrated findings in phase 3A and 3B for interpretation

PHASE 3A – Parents Questionnaire	PHASE 3B – Parent Focus Group Themes
Acknowledging the different roles within the education sector	
• Parents role to provide teachers with relevant health info (77%), allow teachers to access info relevant to learning (75%) and info that concerns safety of others at school (65%). Only just over half of participants saw consent as a role of parents (58%) • Teachers to act in health incident (79%), ensure student privacy (70%), provide social and emotional support (69%) and to be aware of student health, making adjustments with health in mind if necessary (61%) • Schools should provide safe environment (85%) that fosters learning (68%), whilst ensuring teachers are well-informed of health info that affects learning and behaviour (81%)	• *The role of the parent, teacher, school and GP* now and in a DSHISS: the roles of teachers, schools and parents include many of the factors in the questionnaire however are not always a requirement resulting in the need for individuals in these professional roles to respond to the need around them. To do this they need to be more flexible… • *The need for flexibility*: what is expected of each role is based on community need not the "job description" of each role. Some teachers may provide more SEMH support to staff while others may have in school supports to help with this. The role of a school, teacher or GP must be flexible to reflect the changing needs of the community it is based in.
There are significant benefits in a DSHISS	
• Large number of participants saw value in teacher awareness of health (91%, no differences between schools), though less believed that access to health information was necessary (73%) • The ability for teachers to adjust their practice and classroom to provide better academic support (79%) and holistic support (72%) as well as having a greater understanding of learning concerns (69%)	• *The ability to provide tailored support for greater social, emotional, and academic development:* with a DSHISS, teachers will be able to adjust teaching and classroom environments, and support student to overcome their health concerns • *Improved day-to-day safety:* A DSHISS can assure critical information is shared efficiently to help prevent and react in

- Teachers and schools able to provide safer environments and act in health emergencies (79%)

medical events. A DSHISS will assist teachers in keeping their students safe.

There is a potential for harm that must be mitigated

- Misuse of information was a major concern for participants due to the risk of discrimination (56%) and labelling of the student or whānau (60%)
- Concerns around the sensitive natural of some health information (60%) highlight the need for limitations around what information is shared
- Lack of control and inclusion of parents was a concern, especially in what information is shared and who has access to that information (54% respectively)

- *The dangers of mis-interrupted and misused health information:* significant risks must be considered is health information is shared. These risks need to be understood in order for them to be appropriately minimised
- *Adding to an overburdened and under-resourced sector*: there is potential for a DSHISS to add to the expectations of teachers

Solution-focused Implementation

- Limitation needed around what information is shared and who with. Some information should be shared readily (e.g. hearing and vision (89%) and life-threatening (84%)) while others are more sensitive (e.g. mental health 71%) or un-necessary (53%). Classroom teachers and health stuff considered top of list of who should have access (75%, 71% respectively)
- Consent should be opt-in (60%)
- Benefits outweigh the risks ($M = 3.56$, $SD = 1.09$)

- *Need for clear policies and guidelines:* to overcome barriers and minimise the risk, clear guidelines must be implemented. Having clear expectations and process will empower teachers to use the information and apply it effectively.
- *Prioritising empowering relationships with whānau:* building relationships the centre around trust is vital in ensuring parents are included in the process and help with consent.
- *Justified access and the development of a traffic light DSHISS*: utilising the benefits and acknowledging the potential risks, the DSHISS can take a considered approach to implementation that minimises the risks and empowers teachers to use it efficiently.

both the questionnaire and focus groups. Their discussion focussed on the increased ability of schools to provide a safe school environment and the teacher's ability to provide tailored support for individual students.

Participants saw a DSHISS being one way to facilitate sharing knowledge that would assist the ability for teachers to act, and act appropriately, in medical incidents, and for schools to provide safer areas for children (Szefler, 2009). For example, knowing how to react when a child comes in breathless or having a reaction to an allergy. If they are aware of a child's asthma (or other health concern) and how to manage that within the school environment, they can make decisions quickly on what action to take, rather than delaying any treatment due to unawareness (Wodrich, 2005). This action requires teachers to have precise information and direction if an action was needed.

The same direction is needed for teachers to make appropriate adjustments in the classroom (Cook et al., 2017; Cunningham & Wodrich, 2006). Participants saw a DSHISS is one way to facilitate adjustments in and out of the classroom that improves the child's holistic welfare, i.e. their learning, their SEMH and their physical well-being. In order to do this correctly, teachers need guidance and resources to adjust the environment appropriately. Whether these adjustments are within a physical environment, their professional behaviour management, or their teaching, teachers need to be provided with the resources to identify what is the needed for best practice, so they are utilising the DSHISS to its full capability (Thies, 1999).

Sharing student health information with schools and teachers could also assist whānau (Dryfoos & Maguire, 2019; Dryfoos et al., 2005). Focus group participants highlighted the benefit of taking the onus of parents and whānau to disclose health information about their child. These participants noted

the burden-like responsibility it is to discuss their child's medical information to every teacher the child has. For transient whānau, families with multiple children, or schools that have high staff turnover, participants noted that sharing health information can be a cumbersome activity and can lead to parents forgetting to disclose relevant information. The health information system acts as a safety net to this burden, with those conditions not disclosed by whānau due to forgetfulness or even embarrassment, the information is shared and available for teachers and schools to appropriately use.

There could also be benefits for GPs due to bi-directional data sharing. While many diagnostic tests for behavioural, mental health and child development often rely on teachers input (Darling et al., 2019; Malhi et al., 2008), diagnoses are not routinely shared with teachers. Participants discussed the role GPs as medical professionals could play in assisting teachers on how best to utilise health information, pointing out the opportunity for bi-directional sharing, and having GP's assist in monitoring what information is shared. While schools are to provide safe environments for its students as discussed in the questionnaire (85%), the focus group noted how schools could provide a physical space of community and be a driving force for positive change, particularly around public health. Examples of the schools in Northland who underwent supervised teeth brushing programme demonstrates, as long as those schools are well supported in programme delivery, the place schools have in public health promotion (Clark, 2017).

6.4.2. *Understanding perceived risks and the motivations behind them*

The risks of sharing information were focused on by participants in both the questionnaire and the focus groups. Many of these risks crossed over into the roles of the parent and teacher theme, though ultimately, they were identified as concerns that needed to be addressed if a DSHISS was to be established. A small proportion of participants were concerned about whether teachers were trained

well enough to access medical information (21%). Without training, teachers may inaccurately act on information about a health condition which may result in misuse or misinterpretation (Thies, 1999). Alternatively, if sharing student health information were to be routinely integrated into the education sectors, teacher training programmes (both in new teacher training and professional development for existing teachers) would reflect the integration, with teachers being taught how to utilise the information shared (Thies, 1999). It is important to note that sharing health information with teachers does not mean the teachers are to provide medical intervention. However, it does allow an opportunity for teachers to understand their students' needs and support them with consideration of these needs.

Misuse and misinterpretation were main points discussed by participants both in the questionnaire and focus group. Along with misuse and misinterpretation, the loss of control for parents was also a concern. This concern was carried through the questionnaire into the focus group, with participant concerned with parents being unable to control what is shared and who with (54%), and not being able to access the information themselves (46%). This lack of control concern was further developed into the lack of inclusion of the parent and the disintegration of the teacher-parent relationship which can cause less willingness to share information due to lack of trust (New Zealand Data Futures Forum, 2017). Extra detail given by focus group participants highlights an important question from parents. If a DSHISS was to be implemented, how do parents fit in, or will parents get left behind? These concerns might extend to parents not wanting to be unaware of their child's day-to-day and falls back to parent's role of being the child's guardian.

Finally, concern about the lack of resourcing for teachers was an important point bought up in the phase 2A's thematic analysis and further discussed in the focus groups. Participants questioned the

readiness of schools and teachers to effectively utilise the shared information, especially as teachers are already under significant pressure, struggling with high teacher-student ratios in the classroom as well as the growing complex needs of NZ children (Roy, 2019; Whitehead et al., 2000). If teachers can access health information, will they have time to seek out the information and will they have the resources to support the child based on this information? This was an extremely pertinent question for participants to consider as teachers find themselves at increased risk of burn out (Arvidsson et al., 2019; Oberle & Schonert-Reichl, 2016). As a result of this increased risk and lack of education resourcing, significant teacher-strike action was taking place in New Zealand (Roy, 2019).

6.4.3. *Hearing whānau: overcoming barriers to implementation*

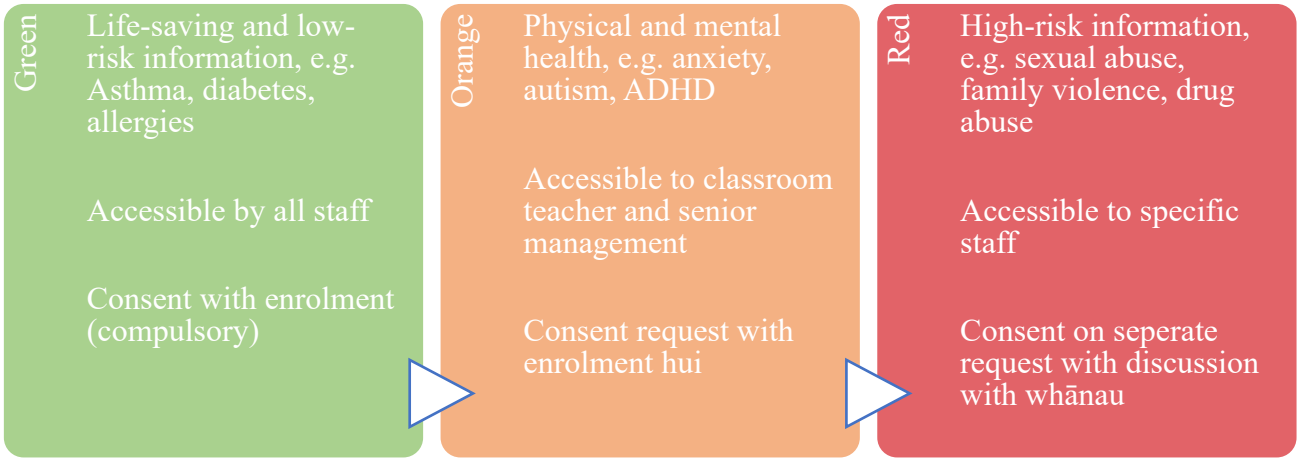
Focus group participants were intent in not only discussing their concerns about a DSHISS but also in providing their skills to minimise these risks, extend the benefits where possible and begin discussing what a DSHISS could look like if done right.

A tiered approach

The idea of a tiered approach to DSHISS structure was discussed, which helped minimise concerns around how to limit what information is shared and with whom. Previous literature has explored tiered consent approaches to share health information for genome research, with participants preferring restricting access, especially when sharing their child's information (McGuire et al., 2011). Here we see the development of a DSHISS working in the current context where certain information is thought of as being more sensitive than others. The development of the tiered approach included participant discussion around consent, who should have access to different levels of health information and where certain health information would appropriately fit. Figure 6.3 displays an example on the three varying levels a DSHISS developed in the analysis.

Figure 6.3

A three-tiered, traffic-light DSHISS



It was important that within the traffic-light system that policies regarding how to access and manage health information are in place. These policies need to be integrated within the system to ensure risks are minimised, teachers feel empowered to use the system, and parents feel safe in knowing that their child's health information is being considerately managed. This integration also needs to set up a staff member who can act as a data steward for the system in case any breaches in confidentiality and privacy occur. A data steward provides parents with additional security that proper process is being followed and should be approachable if parents have any concerns (Laurent, 2005).

Acknowledging the need for whānau inclusion

One concern of parents and whānau was the potential for a DSHISS to impact relationship building between whānau, schools and teachers negatively. The inclusion of parents in their child's education was highlighted in both the questionnaires and focus groups, as well as by parents in phase 1. Parents and whānau are intrinsically linked with their children and have a legal and ethical role as guardians and protectors of their child's health information. They must be included in the process as they provide consent for the information sharing in the first instance. Participants described how having

solid relationships with their child's school or teachers has meant they feel more able to pass on sensitive information. It is crucial that these relationships are prioritised and built on a sense of trust, so parents feel safe in consenting to access, particularly the orange- and red-tiered information (Adams & Christenson, 2000; American Federation of Teachers, 2007; Hughes & Kwok, 2007).

Improved resourcing – ensuring teachers are well-supported

Focus groups participants also highlighted the need for extra resourcing and the potential for bi-directional sharing with GPs. In order for teachers to use shared information effectively, guidance on how to use shared health information in the school environment as well as suggestions for extra support needs to be provided (Cunningham & Wodrich, 2006; Graham et al., 2011). The potential for bi-directional sharing is a novel concept, where teacher and GPs can share certain pieces of health data to improve the outcomes for the child. Participants highlighted that teachers are better placed than others to notice changes in a child's behaviour, mood or well-being due to children often spending 6-7 hours at school compared to 4-5 waking hours at home. Currently, teachers' perceptions are already required to help medical professionals in diagnosing, particularly behavioural concerns such as ADHD (Darling et al., 2019; DuPaul et al., 2001). A bi-directional DSHISS would improve this process as the questionnaires may be accessed via a digital system, and thus, the information needed to make the diagnosis occurs without delay.

6.4.4. *Limitations*

This section outlines several limitations specific to phase 3A and 3B. The overall strengths and limitations of the entire doctoral research can be found in Chapter Seven (see section 7.4). One limitation that requires acknowledgement is the low response rates in phase 3A from School B and C when compared to School A. While effort at School B was ceased early due to the unprecedented

events of 15th March 2019, School C had a low response rate despite various approaches taken to improve these rates. Remembering the lower decile rating of School A, it could be a case in response bias, where participants of lower SES are more likely to respond to surveys than participants of higher SES (Groves & Couper, 2012). However, this hypothesis is at odds with other research where higher SES have higher response rates than their lower counterparts (Jang & Vorderstrasse, 2019). As a result, findings may be skewed and not appropriately represent those eligible to complete the questionnaire from both School B and C.

While the impact of the 2019 Mosque attack may have impacted response rates, it must also consider the impact the attack may have had on participants views on information sharing in general. There is often a perceived trade-off between liberty (and the privacy it should afford) and security when considering information sharing (Dornan, 2011). Events that invoke a general feeling of vulnerability, such as the March 15th terror attack, can often navigate the general public towards accepting greater information sharing. This reaction is due to the public acknowledging the need for information sharing to feel safer and loosening their control of personal liberties and privacy.

Another limitation is the small number of participants who contributed to these focus groups mean these results do not give a full representation of the broader, more diverse range of parents in New Zealand. None of the participants were male, nor were they fathers. None of the participants could speak from the unique perspective of Pasifika or Asian cultures. In work completed by the National Research and Evaluation Unit (2013), the experiences and attitudes to information sharing are vastly unique between cultures. The dawn raids of the 1970s for Pasifika created a strong sense of distrust which profoundly impacts many Pasifika beliefs around government information sharing (Krishnan et al., 1994; Marriott & Sim, 2015; McFadden, 2015). Asian cultures, on the other hand, are more

positive around information sharing according to the National Research and Evaluation Unit (2013). Māori representation (16% Māori in questionnaire and 20% in focus groups) was similar to the population statistics (16.5%; Statistics New Zealand, 2018). Future research should consider purposely sampling Asian and Pasifika parents, and fathers, in order to illicit a more detailed interpretation of these cultural, role and gender-specific perspectives.

Most participants also came in with positive beliefs around the idea of health information-sharing (when matched to the participants' questionnaires answers, 60% of participants agreed that the benefits of sharing student health information outweigh the risks, 10% were neutral, 10% disagreed and 20% strongly disagreed). While a conscientious effort was made by the interviewer to include every participant in the discussion, allowing all participants to express their views, those who had less favourable views toward information sharing may have felt uncomfortable offering these views in the focus group setting. The research attempted to consider homogeneity by keeping discussions within participating schools. However, this may not have been enough homogeneity for participants to all voice their opinions comfortably (Acocella, 2012).

6.4.5. *Where to next?*

This chapter discussed the perceptions of parents when thinking about sharing student health information. Participants were able to consider a well thought on DSHISS system that considered the need for limits on who could access and what information is shared, as well as a way to compartmentalise health information into three groups.

Chapter Seven Discussion

This chapter examines four main areas. The first section discusses the first aim and establishes the need for intervention for children who are experiencing concerns with their health and well-being. This section will utilise the health profile of children identified with low oral language ability to justify the need to take an early intervention approach, so all children are given an opportunity to thrive in the school environment. The second section discusses the second and third aims and will contextualise themes developed from teacher and parent attitudes and beliefs around sharing student health information. These themes give insight into the changing nature of the education sector, how a DSHISS may be perceived by the public and consider a solution-focused, collaborative approach to implementation. The third section will examine the implications of this research, drawing on findings across all three phases as well as key legislative principles for a collaborative implementation of a DSHISS. Finally, the last section will analyse the strengths and weaknesses of this research, a personal reflection of the study and consider areas for future research.

7.1. A health profile of children with low levels of oral language ability

Development of language skills is vital to school success and educational attainment (McLeod et al., 2019). However, poor health and health concerns can impair this development (Joe et al., 2009) and exacerbate the subsequent effect of late-developing language and literacy skills (Case et al., 2005) . Despite the life-long impact of early adverse health, the empirical evidence of overall rates of poor health in schools is surprisingly lacking. Gracy et al. (2017) explored rates of health barriers to learning in the USA, such as uncontrolled asthma, vision problems, behavioural and mental health concerns. These health barriers to learning were found more prevalent in those in low socio-economic areas and children identified as non-European. This doctoral research found over half of participants (55%) in a low SES area identified at least one concern with their child's health.

Rothstein (2011) in particular noted that children from low SES areas are twice as likely to have vision problems, hearing concerns, respiratory and dental illness and are less likely to receive treatment for these concerns. These children may have been experiencing these health concerns before entering school, and thus their health may be one of the contributing factors to their low oral language ability along with low SES (Rothstein, 2011).

Left untreated or unmanaged, the health concerns discussed in phase 1, can lead to low school success and subsequent adverse life outcomes (Herrera & Little, 2005; Lynch, 2003; Yiengprugsawan et al., 2013). The prevalence of concerns with vision (12%) and hearing (19%) is likely to impact the development of early oral language skills (Gillon, 2017). This finding would align with prior research where visual acuity, hearing ability and ongoing ear infections can impact oral language development and learning (Briscoe et al., 2001; Stevenson et al., 2015; Wang et al., 2011; Winskel, 2006). Almost nine out of ten (89%) parents who identified a behavioural concern also identified at least one other health concern. Similarly, 94% of parents who identified a learning concern also identified a further physical health concern. This finding may indicate the impact physical health conditions has had on these students' behaviour and learning (Carroll & Hurry, 2018; de Bildt et al., 2005; Hart, 2010).

The impact of poor behaviour is already managed in the classroom by teachers (Teaching Council New Zealand, 2017). However, the ability of teachers to implement effective behaviour management can depend on the underlying causes of this behaviour. Over one in four (29%) parents identified more than one area of concern which may have a compounding impact their ability to acquire literacy learning and school success (Thies, 1999). Without intervention, those children experiencing health concerns combined with low academic ability can lead to further concerns with behaviour and

mental health (Adelman & Taylor, 2006; Gracy et al., 2017), along with adverse outcomes that can follow them right through to adulthood (Lynch, 2003). However, if appropriate and timely interventions are established, these adverse outcomes may be mitigated.

Many of the discussed health barriers to learning can be managed in the school environment. Results from phase 1 highlighted the potential of early identification of a health concern and subsequent intervention. Two children in this study had received previous professional support for their speech and were not identified as having a clinically significant speech difficulty by researchers (Gillon et al., 2019). This finding could highlight the success of the early professional intervention, whereby a speech therapist may have supported the child through resolving speech difficulty. Even sharing information about chronic or re-occurring illness with teachers may allow for classroom intervention. Cunningham and Wodrich (2006) discussed how, armed with information of a student's T1DM diagnosis, teachers were empowered to make appropriate classroom adjustments that meet the students T1DM-specific learning needs.

With the right professional support and early intervention, children experiencing health concerns, such as speech difficulties, may overcome barriers to learning and development, and reach their full academic potential (Gillon et al., 2019). Some health concerns will be better managed in classrooms than others. Simple classroom adjustments or interventions, such as seating a short-sighted student at the front of the classroom, can overcome health barrier to learning without requiring significant resources. However, support for other conditions, such as mental health conditions, that require one-to-one management may not be able to be effectively managed in the classroom due to funding constraints and teacher capacity. Resourcing and capacity are still significant issues in early

intervention strategies and as such, health concerns that require easier and inexpensive intervention will be better managed than those that require a higher input of resources.

For teachers to manage any health barriers to learning, they need to be aware of their student's health. There is no current empirical evidence on rates of disclosure of student health concerns to parents, nor the rates of classroom adjustments made due to health concerns. The lack of evidence highlights the lack of recognition of the part health can play in school success and may point to an opportunity for targeted early intervention if health information is shared. There are many reasons parents may not disclose student health concerns to teachers, including fear of judgement and not knowing the impact poor health can have on learning. Research by Kim (2019) discovered similar findings between parents and teachers when investigating academic ability in young Pasifika students. A similar finding of positive bias by parents was noted in this study and by the Ministry of Health (2016a), with parents reporting their children had good overall health despite multiple health concerns. Parents may be more likely to share information if parents understand how the information is relevant to their child's learning and welcomed by school staff. If student health information were shared digitally and routinely, with the right professional support and resources, teachers might be empowered to explore interventions to help their students overcome health barriers to learning (Thies, 1999). Participants in this study displayed an openness towards teachers being able to access student health information with the caveat that consent to access is given as an opt-in strategy.

Phase 1 demonstrates the potential health concerns faced by some of New Zealand's most vulnerable children. These children are already having to overcome significant barriers to school success (low oral language skills and low SES) as well as over half experiencing health concerns that may add additional health barriers to learning. Evidence suggested that early identification, classroom

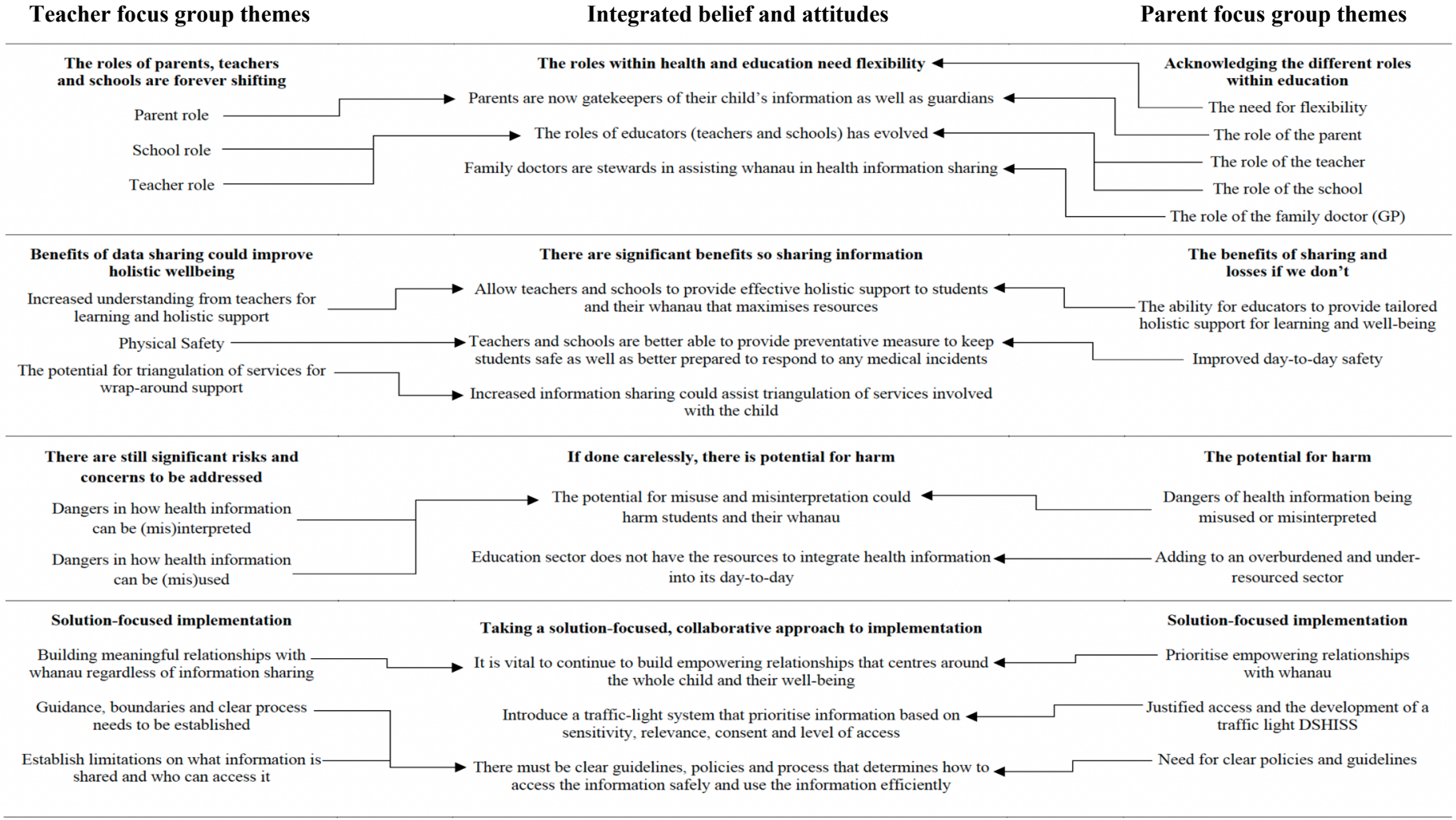
adjustments and intervention can support students to overcome these barriers (Cunningham & Wodrich, 2006; Dewalt et al., 2004). However, teachers currently rely on parents to disclose this information before they can make these adjustments or establish any interventions. With their positive bias towards school success and health (Kim, 2019; Ministry of Health, 2016a), there can be a significant delay in teacher awareness of health barriers. More routinely, digitally shared health information may improve these delays and allow for targeted support for students with certain health conditions. This level of data sharing is generally supported by parents and may assist schools in the early management of health barriers to learning.

7.2. The perceptions, attitudes and beliefs of parents and teachers

Sharing information can be a polarising subject (Office of the Privacy Commissioner, 2016). The polarising nature of a DSHISS requires the critical, grassroots stakeholder groups be included in discussion around the appetite, development and implementation of such a system. Often those grassroots stakeholders and organisations are left out of consultation process, favouring larger government and high-level input (Flores & Samuel, 2019). However, those stakeholders provide practical guidance and consultation. For a DSHISS, consulting teachers and parents is key to understanding the eagerness of these groups to consent to and utilise the shared information. Other important stakeholders include GPs, school staff and other health professionals that may have a role in what information is shared and how it is utilised. Each of these groups will have their own perceptions and attitudes, based on their personal and professional experiences, with many tensions likely between groups. Due to resource constraints, this doctoral research chose to focus on establishing the perceptions of teachers and parents. Figure 7.1 demonstrates the major themes and relevant subthemes developed in phase 2 and 3 and how each theme and subtheme was integrated to

Figure 7.1

Similarity of major themes from phase 2B and 3B



develop the overall findings discussed in this chapter. This section will discuss homogeneity and heterogeneity in teacher and parent perceptions of themes.

7.2.1. *The roles within health and education need flexibility*

Discussion about the different roles of teachers, schools and parents was prevalent throughout all study phases and is a major theme developed in this research. Teachers and parents had similar views on parent, teacher and school roles, with the need for flexibility woven across these views. Parent participants also considered how GPs could be involved with a DSHISS. This section will discuss the similarities and differences between participant attitudes toward the *Roles within Health and Education* theme and relate these findings to previous literature.

The roles of schools and educators are continually evolving to matching mounting research on the factors that add to the complexity of managing and teaching children in a classroom environment (Bolstad et al., 2012; Gracy et al., 2017; Lewallen et al., 2015). There is an expanding responsibly on schools and teachers to support children and their well-being (Community and Public Health Te Mana Ora, 2020; Lewallen et al., 2015). Similar to findings in Lewallen et al. (2015) and the movement of educational theory and culturally response practise (Diamond, 2010), participants noted the growing expectations on teachers to adopt a whole-child approach, one that considers learning within the context of their social, emotional and physical well-being, as well as student whānau and community.

The Teaching Council New Zealand (2017) describes the need for teachers to manage learning and maximise student physical, social, cultural and emotional well-being in the professional teaching standards. Participants acknowledged the impact of student's

behaviour, SEMH needs and physical illness on academic achievement ("…*health issues can affect a child's well-being and learning" – School A parent*). This acknowledgement describes that while their role in driving academic learning remains a priority, there is an increased need for teachers to understand how social factors can impact a student's ability to learn and how to mitigate these factors (Hartas, 2011). This finding is supported by Lanier (1997) who discussed teachers as multifaceted professionals that *"…counsel students as they grow and mature – helping them integrate their social, emotional and intellectual growth…" – Lanier (1997, pg.2).*

Expectations that vary from school to school as the roles of teachers are school are becoming more responsive to community needs. Hwang (2008) highlights that this flexibility can lead to blurring of where a teacher's or school's role begins and ends. This blurring is particularly troublesome when teachers start to feel overextended in supporting a student in a particular way and often results in a higher risk of teacher burnout (Oberle & Schonert-Reichl, 2016). Both teachers and parents discussed burnout, exacerbated by the lack of resources for teachers and high teacher-student ratios. This concern has recently had implications for the education sector in New Zealand. Burnout was a concern debated in recent strike action, where primary and secondary teachers participated in several strikes that advocated for more significant resourcing among other things (NZEI Te Riu Roa, 2019).

Both teacher and parent participants highlighted how schools across New Zealand are taking a much broader approach to learning. The introduction and continuation of public health initiatives and integration of community-based programmes were seen by participants as school forming an integral part in public health and communities as well as providing a safe

space for students, both physically and mentally. These ideas are supported across the literature (Community and Public Health Te Mana Ora, 2020; Kolbe, 2019; Lewallen et al., 2015). The increase of health and safety practices and guidelines has seen the responsibility of schools to keep their students safe become a top priority, while there has been an increased demand for schools to play a more prominent role in providing sex education, drug and mental health awareness, as well as managing bullying and harassment (Te Kete Ipurangi, 2013, 2014, 2015).

While schools still encompass a place of learning, participants saw some schools taking on tasks historically thought of as happening at home. An example of this is the introduction of breakfasts in schools (Kickstart Breakfast) and the Kidscan "Food for Kids" initiative to improve both learning ability and health (KidsCan, 2019; Wilson et al., 2018). Health promotion programmes such as these have developed in response to community needs, particularly in areas of deprivation and highlight the growing part schools play in supporting its students and community ("*... we put much more attention on the social and emotional needs of the children… because the community has changed, the needs of what children need at school is changing*" *– School A kaiako*).

Both teacher and parent participants saw parents as guardians of their child's information, highlighting the significance of two Te Ao Māori values, rangatiratanga (self-determination) and kaitiakitanga (guardianship). With the increase in the integration of IT, these values are vital to ensuring children hold their mana (authority, prestige, spiritual power). This development of technology has required parents to provide greater kaitiakitanga over their child's information ("… *we are the ones that keep our kids' mana. We hold it. No one else*

will hold it like we do" – *School A parent*). This role includes the ability to consent for sharing of health information and gives parents the final say over what information is shared, and whom with (Ministry of Education, 2019).

Parent participants in phase 3 only discussed the role of GPs in sharing student health information. As the leading healthcare provider to whānau, GPs play a vital role in collecting and managing health information. Such a role takes significant levels of trust from the whānau (Towle et al., 2006). Participants, however, were able to give examples of occasions where medical professionals have shown disrespect, demonstrating how the profession needs to prioritise building trusting relationships for patients to feel comfortable disclosing information. This need for relationship-building is particularly relevant for Māori and Pasifika patients, who due to having experienced poorer access and treatment have established generational distrust for the health sector (Jansen et al., 2009).

7.2.2. *There are significant benefits to sharing student health information*

Participants across phase 2 and 3 had a slightly positive preference for sharing student health information and were able to point out the value and benefits that could come from a DSHISS for both acute and chronic health conditions. Similar to Davidson et al. (2015), participants saw benefits in information sharing as being better able to provide a more efficient service resulting in safer and more supportive environments. The benefits of a DSHISS in this research centred around practical and holistic support in the classroom, safety, and triangulation with other services involved with the child.

Participants across phases 1-3 saw sharing student health information as a way to ensure teachers have all the critical information to prevent and react to medical incidents. While the role of teachers is not to be health professionals, they, and the school, do have a responsibility to ensure the school environment is safe and that students can receive medical care without delay. The *School Safety* subtheme found across phases links into the expectations and roles of schools and educators, as there are standard health and safety requirements that must be meet day-to-day (Ministry of Education, 2017) as well as necessary flexibility for school staff to respond to medical incidents. Sharing health information certainly has potential to improve school safety, especially for students with life threatening conditions (Student Rights NZ, 2019; Zimmerman et al., 2016).

Participants across phases also highlighted the ability for teachers to support students more holistically, providing both practical learning support as well as SEMH support. Thies (1999) supports the idea that sharing health information would help teachers provide greater holistic support. However, Theis (1999) also highlighted that appropriate resourcing is vital to support teachers in utilising the shared information in the right way. The holistic benefits of a DHSISS discussed by participants, integrates social, whānau, physical and mental well-being, and mirrors the philosophy of te whare tapa whā model (Durie, 1998). The benefits of a DSHISS discussed by participants integrate the four pillars of Durie's (1998) te whare tapa whā model (discussed in chapter one) and could improve taha whānau as schools are better informed to offer or suggest services that could assist the whānau, as well as teachers supporting students in their social well-being. The acknowledgement of taha whānau by participants in phase 2 and 3 is consistent with Bennett et al. (2002), who identified the link between family contributions and children's acquisition of early literacy skills. The support

was perceived to impact the academic needs of the students, as well as their SEMH. Taha tinana and hinengaro could improve as teachers can provide tailored resources, allowing children to learn in a safe space, overcome any health concerns and promote social and emotional well-being (Graham et al., 2011). A DSHISS could also help teachers provide tailored academic supports (Cunningham & Wodrich, 2006), improving the student's ability to learn and their self-concept as a learner, thus improving taha wairua (Manning, 2007).

One difference in benefit themes discussed between phase 2 and 3 was the inclusion of triangulation as a subtheme. Teacher participants saw the potential for more efficient triangulation with services which may be involved with their students if health information was readily accessible, allowing for bi-directional information sharing. This subtheme is consistent with Thies (1999), where students benefited from collaboration and information sharing between health, education and social services. In the New Zealand context, similar successful triangulation is established across sectors. New Zealand's Accident Compensation Corporation utilising medical professionals for physical treatment, educational facilities for vocational rehabilitation (Accident Compensation Corporation, 2020a) and assistance (teacher aides) for children at school with permanent disability (Accident Compensation Corporation, 2020b). Rest homes and elderly care in New Zealand is also reaping the benefits of inter-agency collaboration. The Home Care International Residential Assessment Instrument (interRAI-HC) provides reliable empirical data that considers an older person's psychosocial factors along with physical and mental health (interRAI New Zealand, 2020; Schluter et al., 2016). The interRAI-HC bring in data across health and social development and points to opportunities to improve the holistic well-being of the individual. Triangulation

could also mean sharing advice on how to manage a student's health concern within the school environment could be shared directly from health practitioner to teachers and parents. This direct health information sharing could increase consistency in behaviour or health management plans that can be carried out at home and in the classroom and helps provide effective behaviour management at school (Hart, 2010). The addition of other organisations outside the school environment, such as Oranga Tamariki, could see better use of resources (Dryfoos & Maguire, 2019), minimising any conflicting advice given and acknowledging what support has and has not worked for whānau in the past.

7.2.3. *If sharing health information is done carelessly, there is potential for harm*

The potential of privacy breaches, misinterpretation, and misuse was raised in phase 1 and continued throughout the study by teachers and parents in phase 2 and 3. Parent participants (phase 3) also discussed the potential cultural risks associated with information sharing and the additional need for resourcing if a DSHISS was to go ahead.

Participants across all phases covered different types of misuse and misinterpretation, such as labelling of students, judgements about the student or their whānau based on the shared information, and schools using the information to exclude students at enrolment. Labelling health concerns, particularly for mental illness, often contribute to low self-esteem in children and young adults (Angermeyer et al., 2004). Exclusions of children with health or behaviour concerns could be further damaging as the child may struggle to enrol at school, further exacerbating delays in formal academic instruction. The nature of the information sharing contributes to the need to consider the risks and how to minimise them. Organisations and agencies all face similar risks, especially those organisations that collect, manage or use

sensitive information (Gil-Garcia et al., 2009; National Research and Evaluation Unit, 2013; Richardson & Asthana, 2005). Participants across all phases of this research were concerned with potential misuse, misinterpretation and issues around privacy. Over the past decade, there have been several significant privacy breaches and abuse of information in New Zealand. These breaches are felt across sectors and have included health (Hunt, 2019), social development (Davidson, 2017), and private enterprise (Foxcroft, 2019). The PC is currently investigating a major health breach in New Zealand where personal information about patients with COVID-19 were leaked to the media (Office of the Privacy Commissioner, 2020b). The media coverage of these breaches weigh on individuals and can often influence individuals' views on political issues (Huebner et al., 1997). One of the many examples given by focus group participants was nationally reported in the media (Carroll, 2019) and demonstrated the potential for real harm when information is misused or misinterpreted, and the salient impact of media.

Oranga Tamariki came under scrutiny in 2019 when the organisation uplifted newborns from their mothers based on information they had on the newborn's whānau. This misuse of information, in that Oranga Tamariki acted inappropriately based on information they had collected on the whānau, was made public and highlighted the potential for severe harm and racial profiling that occurred due to misuse of shared information (Reid, 2019). There is an established fear of certain organisations involvement, most noticeable in this research the fear of Oranga Tamariki, which could be a barrier to sharing health information regardless of the benefits.

Parent participants in the focus groups noted another concern around the need for more resourcing to support increased awareness of health concerns through health information sharing. Participants highlighted how teachers were over-extended (Roy, 2019), and acknowledged the potential for sharing health information to increase a teacher's workload. This concern is consistent Arvidsson et al. (2019) who identified perceived job demands as a factor in teacher burnout and links back to the increasing expectations on schools and teachers to provide greater holistic support to student and their whānau. Several studies have examined ways to minimise teacher burnout (Iancu et al., 2017), discussing decreased workload (Arvidsson et al., 2019), and increased student engagement (Covell et al., 2009) as ways to lower the likelihood of burnout.

There are significant cultural risks associated with sharing health information. It is vital to acknowledge the cultural factors of New Zealand's indigenous Māori population when sharing personal information. Participants expressed concern for systematic disadvantage experienced by Māori within government services being exacerbated by sharing health information and the potential for a DSHISS to disempower whānau by removing self-determination and inclusion of whānau in the decision-making process:

> *"…I mean we are looking at empowering families, and parents and whānau ora, self-determination, then you can't be taking things away…" – School A parent*

This cultural risk of disempowerment for Māori may be exacerbated by systemic disadvantage, "…*as Māori, I don't feel safe in our* [health and education] *system*" (School A parent). This view is underpinned by Māori and Pasifika experiencing significant

disadvantages in health and SES (Harris et al., 2006) and the continued experience of perceived discrimination found by Houkamau et al. (2017). For Māori, data and information is taonga – something that is considered a treasure or highly prized (Taiuru, 2018). When this information is shared, Tikanga Māori values must be incorporated into the principles of sharing as well as in the day-to-day processes (Te Mana Raraunga - Māori Data Sovereignty Network, 2016). Similar consideration needs to happen for other minority groups in New Zealand, particularly for Pasifika. The dawn-raids are an example of how information was used against Pasifika by the New Zealand government (McFadden, 2015) and has instilled distrust in technology, government organisations and data sharing (National Research and Evaluation Unit, 2013). Without including values from both cultures, there is a genuine possibility of disempowerment for Māori and Pasifika children and whānau.

7.2.4. *Taking a solution-focused, collaborative approach to implementation*

All focus group participants discussed ways to minimise risks and improve the acceptance of a DSHISS, developing ideas that provide a solution-focused approach to implementation. In developing the solutions found in this theme, participants considered concerns and benefits previously discussed in the questionnaires (phase 2A and 3A) to help work through potential barriers to implementation. They built on concerns they had with sharing health information and focused on drawing on benefits to minimise these risks, of which many aligned with Sane and Edelstein (2015) philosophies to overcoming barriers to public health data sharing.

Parents and teacher participants discussed how relationship building was an essential part of a DSHISS. The Office of the Privacy Commissioner (2014) highlighted the importance of building trust in the health sector so that information sharing can occur. Sharing health

information requires a high level of trust, both within the health sector and the education sector. Building relationships between whānau and teachers is crucial in gaining trust (Lips et al., 2009; New Zealand Data Futures Forum, 2017) and allows for better consistency and teamwork between school and home (Lewallen et al., 2015). The improved communication and prioritised relationships between teachers and parents may lead to a more consistent approach to behaviour, health and learning between home and school. This consistency may have significant positive implications for the student (Hughes & Kwok, 2007; Sirvani, 2007). Without this relationship, the benefits of a DSHISS may be muted, or whānau may refuse to give consent to information sharing (Adams & Christenson, 2000). In a broader sense, the importance of relationships is a core value in Te Ao Māori and one that is interwoven into the fabric of New Zealand society through te Tiriti o Waitangi. The Ministry of Education has incorporated the concept of a tuakana-teina relationship which provides a buddy model for learning (Te Kete Ipurangi, n.d.). In this study, participants highlighted how the teacher-parent relationship could act bi-directionally, where teachers can be seen as experts in education while parents as experts of their children. Together this relationship can enable the very best approach to elevating the child's well-being and learning while fortifying their mana.

Sharing health information will require a set of clear guidelines, policies and processes that determine how to access and use the information safely and efficiently. While parent participants believed these guidelines to act as a deterrent from inappropriate information sharing, teachers noted that clear boundaries empower teachers to share and appropriately use student health information within those guidelines. Participants highlighted the need for transparency around who will have access to the information, what information they will

have access to and having a guide that establishes a clear justification for access and subsequent use of health information. Providing clear frameworks, guidelines, and processes will improve cross-government and multi-disciplinary information sharing (Lips et al., 2009). As long as sufficient resourcing follows the shared information (Thies, 1999), these guidelines and processes will ensure teachers are aware of how to utilise the information in the classroom (Wodrich, 2005). Cunningham and Wodrich (2012) raised a vital concern when sharing health information. They found teachers failed to make appropriate classroom adjustments when given more information about their students T1DM. Cunningham and Wodrich (2012) discovered teachers with more information about a disease were less likely to seek professional advice on how to manage that illness. This finding highlights the need for a collaborative approach to informed interventions, where teachers are supported by appropriate professionals on appropriate classroom interventions. If a DSHISS was to go ahead, it is crucial to ensure professional medical advice is integrated into the system.

Participants also highlighted what information they would (and would not) benefit from, continuing the theme established in phase one that limitations on what information is shared are necessary. There was a clear focus on mental health information across all aspects of this study, which highlights the importance of mental health support in the school setting, and sensitivity of mental health information (Damschroder et al., 2007). Similar to Kramer et al. (2006), parents in this study saw mental health as being an essential factor in well-being and their child's ability to learn. The focus on mental health could be a result of the reported increase in mental illness within Canterbury's young people, especially after the earthquakes in 2011-2012 (Blundell, 2018; Johnson & Ronan, 2014).

7.3. Implications for a brighter future

The integration of health and well-being into schools can open up opportunities for students, teachers and whānau (Lewallen et al., 2015). Participants were acutely aware of potential benefits from greater integration, discussing the ability for teachers to understand and teach their student's fully. The integration follows the increasing understanding of the payoffs of multi-disciplinary work. It utilises the skills, availability and access of professionals across sectors for the sole purpose of improving outcomes for children. This integration can begin with allowing student health information to be shared between the education and health sector, taking the initiative to support the well-being and success of New Zealand's children.

7.3.1. *The need for a multi-disciplinary perspective to learning*

The bidirectional relationship between health and academic success can result in a variety of direct and indirect impacts of poor health and well-being. The results from this research identified over half of the children with low oral language ability are bringing health concerns into the classroom, which may be impacting their ability to learn. Without intervention, the long-term health and language concerns can exacerbate further poor well-being and school success (Low et al., 2005; Schluter et al., 2018). Currently, interventions for poor health occurs primarily in the health sector, while interventions for low oral language ability occurs in the academic setting. This intervention strategy ignores the bidirectional nature of health and learning. It focuses on addressing individual concerns rather than providing holistic, child-centric support.

While there has been a shift towards considering the impact of factors outside of education in academic success (Aaron et al., 2008), this research highlights the real-time need for a more

interdisciplinary approach to learning intervention. This approach to learning intervention could help improve school success for children like the ones in this study and can lead to significant economic and social benefits (Allen, 2011). However, meaningful communication between the health and education sectors is pivotal to improving the integration of health in early intervention strategies. With a DSHISS, educators can access the health background of their students and provide targeted early intervention that includes any health factors burdening the student (Cunningham & Wodrich, 2006). By incorporating bidirectional information sharing between the health and education sectors, children may be relieved of their health burden in the classroom, allowing them to concentrate and learn.

7.3.2. *The changing nature of education and its multi-disciplinary impact*

The integration of health issues in schools has already begun, with graduating teaching standards incorporating a whole-child approach to the standards (Teaching Council New Zealand, 2017). The expansion of school and teacher roles demonstrates the transformation the education sector is currently experiencing. Government organisations are beginning to take a more child-centric approach. This approach (where the child is at the centre of every decision) acknowledges the role the whānau has in the child's well-being and highlights the need for whānau to be actively involved in their child's schooling (Oranga Tamariki, 2017). Whānau having this active role helps build a stronger relationship with the school and maximise the ability to work together (Oranga Tamariki, 2017). The demand for more child-centric approaches to teaching, the advancement of information technology (IT) and growing social consciousness is dictating the evolution of the education sector.

Community-based schooling, or full-service community schools (FSCSs), has already incorporated the child-centric and community need approach (Dryfoos & Maguire, 2019) and maybe one way to better integrate health into the education sector. With the discussion from teachers and parents about these approaches seen as the way forward, the education sector may see the emergence of more FSCSs in New Zealand. While some New Zealand schools boast about being "community-lead"(Community Schools Alliance, 2019), FSCSs see the integration of community agencies:

> *"…including primary-care health clinics, dentistry, mental health counselling and treatment, family social work, parent education, enhanced learning opportunities, community development, and whatever else is needed in that school community"* (Dryfoos et al., 2005, p. 8).

FSCSs require several factors to come together to be successful, with findings of this research highlighting some of these factors. These factors include adequate resourcing, multi-disciplinary capability, information sharing ability between sectors and disciplines, and an understanding and acceptance of the social determinants that impact learning (Dryfoos & Maguire, 2019; Lewallen et al., 2015; Voyles, 2012). FSCSs would have a significant impact on other sectors, particularly health and social services. New Zealand's health sector is overburdened, with many regions facing understaffed hospitals, GP shortages and a lack of resourcing that does not meet the current public need (Wilson, 2019). The CDHB acknowledged the strain on health resources, identifying how due to an aging population, the CDHB would be facing an astronomical increase in delivery costs for hospital-level care (Gullery & Hamilton, 2015). In response, the CDHB developed an integrated care model, one that emphasised prevention, primacy healthcare, community-based health setting and placed

the responsibility of health on the patient (with support services input). Gullery and Hamilton (2015) examined the initiative and stated:

> *"The whole-system approach adopted in Canterbury focuses on doing more in the community, making best use of specialised and scarce resources, and doing the right thing for the patient regardless of historical health system and funding silos. At its core lies identifying what is best for the patient, with what is best for the system as a balancing focus, and an emphasis upon empowering clinical leadership" (pg. 114)*

Introducing primary and mental health services into schools for students and their whānau works alongside this integrated care model as it focuses on primary prevention. It could also see a decrease in the need for hospital-level care (Rosano et al., 2012) and improved health outcomes. Sharing health information across sectors through a DSHISS, and supporting schools to implement deliberate, well-resourced interventions may help manage student health and improve school success (Lewallen et al., 2015).

The positive impact of FSCSs is well documented in many western nations (Cummings et al., 2011; Dryfoos & Maguire, 2019). In the New Zealand context, the Ministry of Education piloted a Healthy Community Schools programme (similar to a FSCS). This programme incorporated limited health and social services into nine, decile one, multicultural secondary schools (Ministry of Health, 2009a). Due to their unique social determinants, these students are at higher risk of health concerns and poorer school success (Low et al., 2005; World Health Organization, 2008; Zimmerman et al., 2016). The programme found by providing school-based health and social services, there was an improvement in student access to these

services, increased early health intervention, improved engagement from student and whānau, as well as an improvement in educational outcomes across literacy and numeracy (Ministry of Health, 2009a). These findings highlight the positive impact of increasing integration of health and social services in schools and are supported across the literature (Cummings et al., 2011; Dryfoos & Maguire, 2019; Voyles, 2012). Literature from overseas examples of FSCSs and the Healthy Community Schools programme findings also link to several of the major themes and subthemes across this research, such as the need to foster relationships and whānau engagement (Tagle, 2005; Voyles, 2012), the benefits of increased teacher awareness of health concerns (Dryfoos & Maguire, 2019; Dryfoos et al., 2005; Lewallen et al., 2015) and the ability for more triangulation and collaborative practice (Cummings et al., 2011; Dryfoos & Maguire, 2019; Tagle, 2005). These similarities validate the findings of this study and could imply the implementation of a DSHISS in schools to facilitate an integrative and FSCS approach, may contribute to positive education and health outcomes.

The impact of COVID-19 in New Zealand throughout 2020 has had a profound effect on how children accessed education and required the education sector to embrace the potential of technology and digital systems. In response to the New Zealand government's decision to implement a nationwide lockdown, whereby children were unable to attend learning institutions physically, the education sector quickly put together a digital, online learning package for students throughout the country (Collins, 2020). To address digital inequalities, the New Zealand government provided over 17,000 computers, totalling $88 million, were sent to students across New Zealand. Internet connections for those who previously had no or limited internet access were also prioritised (Sachdeva, 2020). Providing digital resources to ensure every student can continue learning displays a willingness of the New Zealand

government to invest in digital technology that emphasises school success. The response to COVID-19 forced the New Zealand education sector to work with their whānau to ensure all students had the opportunity to continue learning during the pandemic. This response demonstrates the potential for schools to continue to respond to community need and work more flexibly. The data collected in this research occurred before COVID-19 being present in New Zealand and thus does not represent any perceptions developed during and after the worldwide pandemic. Future research could investigate the changes to the public perception of digital technology and information sharing in schools due to COVID-19. It could also investigate whether there was an impact on children's academic outcomes due to the online delivery of schooling.

7.3.3. *Barriers to an interdisciplinary, community-based education system*

Development of any novel initiative requires a critical analysis that contemplates the outcomes and costs associated with such development. By considering the barriers and costs of a DSHISS as well as the costs associated with a FSCS approach, the development of new initiatives can address and overcome barriers to successful implementation.

There must be significant consultation and collaboration with Māori and Pasifika if a DSHISS is to be implemented. There are significant cultural risks that require careful consideration to ensure the inclusion of Māori and Pasifika in the development, their concerns heard and acted upon, and empowered by the use of a DSHISS. Participants across this research also voiced similar concerns. Taking a Te Ao Māori approach to DSHISS development is a starting place, as well as consultation with key Māori and Pacifika entities

such as Te Mana Raraunga – Māori Data Sovereignty Network and Global Indigenous Data Alliance.

Dryfoos and Maguire (2019) discuss a range of barriers to FSCS. The lack of resourcing remained one of the primary barriers to a holistic education system and is a recognised barrier discussed in chapter five and six in this research. The current funding restraints in the health and education sector exacerbate this barrier. Initial start-up costs of a DSHISS and FSCS would require significant pooling of resources from both education and health, as well as an injection of funds from the government. There are several ways to potentially mitigate these costs. The long-term economic pay-offs for better overall health management could reallocate funds from tertiary hospital care to primary health and education sectors (Gullery & Hamilton, 2015; Lewallen et al., 2015; Roy, 2019). However, Dryfoos and Maguire (2019) warn that observation of the full economic benefit of FSCSs can take years. Another way is to utilise already established initiative to minimise these costs. By integrating already established initiatives for mutual gain, the costs of introducing greater child-centric approaches may be minimised and spread across the initiatives. Section 7.3.4 will discuss such initiatives in more detail.

The need to integrate different disciplines faces challenges, particularly where their interests or culture do not align. There are difficulties with confidentiality when integrating and sharing information on a student, similar to the risks considered in the focus group discussion regarding a DSHISS (Adams & Lee-Jones, 2017). It will also require significant work legislatively, as discussed in the second chapter. Development of a DSHISS will require a

robust legislative framework to minimise risks and ensure the public and users feel protected. Section 7.3.5 will discuss the legal implications in more detail.

7.3.4. *Population-based advantages of a DSHISS*

There is also the potential for health information collected for a DSHISS to be utilised for population-level research and interventions. With the appropriate consent and approval, information shared through a DSHISS could help provide empirical data for population-based intervention and research. Currently, the B4SC and interRAI-HC are examples of similar systems that gather information regarding individuals to inform both individual interventions as well as population-based research (Milne et al., 2019; Nishtala & Jamieson, 2017). Information from these systems can be utilised for academic research once information is de-identified, which can then inform public health policy and population-based intervention. Data collected for a DSHISS could also be integrated with big data systems such as the IDI that aims to improved outcomes for all New Zealanders. This research did not discuss the implications of further population-based data use of a DSHISS. Further research is required to discuss the potential for population-based advantages and the ethical, consensual and legislative implications of sharing data in the DSHISS on a national level.

7.4. Other considerations for a DSHISS

In addition to stakeholder attitudes and opinions, there are three other major areas of consideration. While not informed by the findings of this research, they are vital factors to implementing a DSHISS. These considerations include how the DSHISS could fit in with already established services, the potential in population research and the legal and ethical factors of DSHISS implementation.

7.4.1. *Combining with established services for mutual gain*

There is an option to integrate several existing health information systems with a DSHISS. Integration of these systems will require a considered approach to ensure that teachers and other education professionals understand the information shared and can use it. Integrating a DSHISS with already established services may minimise some of the high development cost while also minimising the potential of multiple systems collecting similar information.

Systematic integration

A DSHISS could be modelled off established and successful information sharing systems. Integration with digital systems such as HealthOne (HealthOne, 2016a) and iMOKO (Navilluso Medical, 2016a) could reduce the resources needed as much of the health information that would be shared is stored in these systems. A DSHISS follows a similar ethos as both these suggestions as it would allow teachers the ability to access information about their students and make fully informed classroom adjustments that improve learning. It acknowledges the potential for positive outcomes when taking a multi-disciplinary approach that includes the community in the holistic well-being of children (Navilluso Medical, 2016a). Diagnoses stored in HealthOne and iMOKO could be shared with teachers through a DSHISS and could categorise health information to include the tiered approach discussed by participants in phase 3.

Ensuring professional guidance after information is shared

A DSHISS could also link or integrate services and practises from the Canterbury Mana Ake programme that was discussed in chapter two (Canterbury Clinical Network, 2020). The

focus on holistic well-being aligns well with the ethos of the DSHISS developed in this research as the culture of the two resources will help the integration of these initiatives. After accessing health information about students from the DSHISS, Mana Ake's Leading Lights website would provide information on how to support those students in the classroom and inform teachers of resources and organisations available to them and the student. As a continually developing resource, it provides educator-focussed advice from appropriate medical and health professionals, overcoming any jargon or language barriers to communicating health information outside of the health sector. It could provide users of the DSHISS with appropriate professional guidance on how to best use the information as advised in research by Cunningham and Wodrich (2012).

The potential for integration of other information:

There is also potential for information outside of health and education to be shared. Societal and familial information can have a significant impact on health and education (World Health Organization, 2008). Sharing societal and familial information then could also add more substance to providing child-centric early intervention. This level of information sharing could allow more effective early intervention for children at higher risk of poor health outcomes, low literacy and academic success, and poor long-term outcomes in adulthood (Case et al., 2005). An example of how this level of information sharing could look, or at least begin, is e-Estonia digital society (E-Estonia, 2016). The integration of personal information outside of the health and education sector, and for the entire population, will require significant buy-in and participation from citizens (Barbaschow, 2018). To achieve necessary levels of participation, the government will need to listen to public concerns and ensure the public can see significant value in such a transformational ecosystem.

7.4.2. *Legislation and ethics: current challenges and potential for development*

Considering the legislative and ethical environment is vital when considering a DSHISS as it can help minimise, not eliminate, the possibility of risks (Office of the Privacy Commissioner, 2015) and provide clear guidance on whether information can be shared. The development of a DSHISS must consider the current legislation to ensure risks associated with a DSHISS are minimised, and those involved have clear expectations on the use and purpose of shared information. The legislative and ethical implications must be considered at the start of developing an DSHISS, to minimise foreseen barriers to implementation, primary (for individuals) and secondary (population) use.

There is currently no set principles, ethical framework or specific legislation for sharing health information with educators, apart from the more generic legislative documents such as the Privacy Act 1993, HIPC 1994 and Education Act 1989. If health information is to be shared with education providers for the sake of academic achievement and well-being, do specific principles need to be put in place so that the information is not misused? Do those who will be able to access the information know the seriousness of a breach, and are they prepared to handle this information? Who should have access to the information, and what should the information be used for? The answers to these questions will contribute to the successful development of a DSHISS.

There is an ethical argument for sharing health information (Braunack-Mayer & Mulligan, 2003; Kalkman et al., 2019), with Langat et al. (2011) concluding that sharing health information is a morally and ethically sound default, especially if that information is for

population health. Despite the ethical argument for sharing health information, there is a critical lack of ethical frameworks for sharing information (Kalkman et al., 2019). Braunack-Mayer and Mulligan (2003) discuss the ethical conflict between individual patients' best interest and perceived confidentiality. They emphasise the importance of transparency and communication for patients to minimise perceived confidentiality breaches. Kalkman et al. (2019) highlights the lack of a cohesive ethical framework in health information sharing and put forward factors to consider in the development of such a framework. They conclude that streamlining terminology and harmonising principles into a framework needs to focus on promoting information sharing while building public trust.

The lack of understanding about information-sharing legislation along with a lack of ethical or principle frameworks, is a pivotal barrier to information-sharing according to this research. Individuals are often unwilling to share information due to the lack of understanding of privacy legislation, worried that sharing information may be violating the legislation. The need to consider a vast amount of potentially relevant legislation contributes to a lack of understanding and is particularly relevant for professionals who lack time resources. Trying to navigate the legislation can be confusing, with governments trying to clarify the space so individuals can effectively use the legislation (Commonwealth of Australia, 2019).

The information-sharing space in New Zealand is already undergoing radical change. The move towards a more digital arena and increase in technological capabilities have seen how information change momentously since 1993. As a result, New Zealand's Privacy Act 1993 will be reformed and replaced by the Privacy Act 2020 (Office of the Privacy Commissioner, 2019b). The Privacy Act 2020 immerses itself in the current technological environment. It

will have a significant impact on various other legislative documents that include the 1993 version (such as the HIPC and Education Act 1989). The revised Act will also guide future principle and policy documents which will be relevant when considering introducing a DSHISS.

The development of a DSHISS will require significant legislative guidance and may require its own set of principles and ethics that encompass relevant legislation. By having a framework outlining principles for sharing health information between the health and education sectors, there is an increase in the value of the information being shared. These principles will dictate how information is not only shared but collected, managed, stored and used to ensure that the data is respected and that the individuals or groups where the data has come from feel protected and well informed. As a result, not only may individuals and groups be more willing to sharing information, there will be increased transparency and openness to data sharing. Developing a separate framework that sets out and incorporates the relevant legislation, principles and ethical considerations ensures teachers and parents are aware of the legal requirements associated with the DSHISS.

It is vital that consent for a DHSISS is considered within the ethical and legislative frameworks. Future research should further analyse what type of consent is required for a DSHISS. This future work should discuss whether it is necessary to have varying types of consent (broad consent vs. specific consent) and whether consent is opt-in, opt-out or varies between the two. It should also discuss the discourse around gaining consent, ensuring that the consent process builds trust (Kalkman et al., 2019), highlights reciprocity and solidarity (Langat et al., 2011) and is adequately informed (Braunack-Mayer & Mulligan, 2003).

A framework outlining these principles also allows the establishment of clear boundaries if there is a breach. Breaches in security, legitimacy, privacy or quality of the data occur and can result in individuals or groups being distrustful of the system, opting out and the system being met with substantial hurdles in public perception if not dealt with acceptably. Outcomes like this could lead to a regression in data sharing on multiple levels, thus impacting various sectors and regression of the benefits to communities. There exists an opportunity to incorporate the work done by the NZDFF and existing legislation to create a go-to-guide to information sharing for all sectors that discuss in-depth how sharing information should occur and procedures on how to act when something has gone wrong.

In developing a principle and ethical framework, thought to who the key stakeholders are must be considered. Ministry of Health input will allow HIPC 1994 principles to be at the forefront of the document. Input from the Ministry of Education will allow practical guidance in what information is relevant, how to utilise the information effectively, and who should have access to the system. There must also be discussion around protection and guidance for teachers and school management who will have access to the system. Finally, the input of the PC is vital to ensure that this document follows already established criteria and principles of the updated Privacy Act 2020 and other statutes. By seeking input from these primary key stakeholders, development of principles for multi-disciplinary data sharing between health and education sectors will be balanced between the rules and needs of all stakeholders while ensuring the privacy and security of the health information is a top priority. The inclusion of stakeholders, particularly those with the most sensitive information, along with incorporating ethical consideration, the principles designed by the NZDFF along with current legislation,

will lead to a substantial framework for organisations from a variety of sectors to follow when sharing information.

7.5. Strengths and limitations: with recommendations for future research

This section will outline some of the strengths and limitations of the research. Processes to mitigate the limitations and consideration of the limitations will be noted where applicable and recommendations made for further research were appropriate.

The quantitative component of this research has limitations that are important to bear in mind when interpreting the results. The questionnaires used within each phase of this research (phase 1-3) had not been standardised, and the psychometric properties of the questions and the survey are largely unknown. To minimise the impact of this limitation, two parents and two teachers piloted phase 2 and 3 questionnaires, along with thesis supervisors. Feedback was incorporated into the questionnaires. Several questions were taken from other Ministry of Health questionnaires, which had been developed for nation-wide use. It is also important to mention the potential for non-response errors due to the low response numbers (Groves & Couper, 2012).

Response rates across the phase varied considerably. A strength of this research is the good response rates of participants from low SES areas. Studies that require participation of individuals in low SES areas are likely to report low response rates, some as low as 12% (Jang & Vorderstrasse, 2019; Roberts et al., 2020). Participants in phase 1 and from School A in phase 3 were parents whose children attended low decile school and likely lived in the surrounding low SES area. Despite this, phase 1 achieved 60% response while 71% of School

A in phase 3 responded. This contrast to the literature may be due to the multi-pronged approach to data collection employed. In phase one several techniques, some of which were quite resource dependant, were employed, including one-on-one assistance, community workshops and via telephone. The researcher for School A had built an excellent relationship with the school community, however lacked the resources to build this relationship in School B and C. There was also an excellent response rate (90%) from teachers in phase 2, which may highlight the interest of teachers in the topic. Future research should consider the effectiveness of a multi-pronged approach that builds key community relationships as a way to mitigate nonresponse in low SES communities.

Analysis of the teacher perceptions may have influenced analysis of the parent perceptions due to researcher bias and analysis of the parent perceptions occurring after the teacher perceptions. Researcher bias is considered as undesirable within quantitative methodology; however, the complete absence of researcher bias is thought of as unattainable in the qualitative world (Cox & van Gorp, 2018). Reliability analysis from an independent rater was employed in each phase to mitigate researcher bias. This rater was asked to check comments placed into themes, and any disagreements were discussed until the disagreement was resolved. While the analysis acknowledged potential bias and attempted to minimise it, the themes between teachers and parents were similar.

What participants thought of health information may also have differed as the questionnaire provided no direct definition of “health information”. During the development of phase 2 and 3 questionnaires, the researcher considered and decided not to include a definition due to the impact a definition may have had on attitudes and participants abilities to be creative in how

a DSHISS could work. Without a direct definition of health information, participants may not have been discussing the same concept of health information as others.

This research examined a specific intersection of the attitudes of parents and teachers with a potential DSHISS. It was open to education professionals and parents across three schools in low to high SES suburbs in an attempt to explore differing views across these schools. The convenience sampling method employed limits the likelihood of these findings to be representative both nationally and regionally (Etikan et al., 2016), thus findings from this research may not reflect the attitudes of parents and teachers across Canterbury or from other regions throughout New Zealand.

This research focused on parent and teacher perspectives. It did not consider the perspectives of GPs and other relevant government organisations and parties that could be impacted if student health information was to be shared. Future research needs to include the perspectives of these stakeholders as they play an essential role in health information gathering, sharing and use. Similarly, the research was embedded purely in the hypothetical, where no decided action toward health information sharing in school was imminent. The views reported in this work may not reflect the same views if sharing health information with schools was more imminent.

Participants who identified as Pasifika or male were underrepresented in both the teacher and whānau groups in phase 2 and 3. The education sector has historically been classed as a female-dominated area, while mothers are often more involved in their child's school administration (Drudy, 2008). This piece of research reflects these historical gender

disparities due to the low male participation rates for both kaiako and parents. Future research may benefit from seeking out views from male teachers and fathers.

The researcher addressed concerns for lack of cultural participation early in the development of this research. In an attempt to mitigate any disparities with Māori inclusion with this research, the questionnaires were designed in partnership with one of the University of Canterbury's Māori Development Group, incorporated te reo Māori and took a considered approach to be culturally responsive in the collection phase of the research. This partnership may have had some impact on Māori participation rates at 15% and 16% for teachers and parents, respectively. Pasifika and Asian participants, however, were underrepresented. New Zealand schools are becoming increasingly multicultural, and the inclusion of a variety of attitudes from different cultures is more critical than ever (Education Review Office - Te Tari Arotake Mātauranga, 2018). The 2018 census found increasing diversity in 5-9 year-olds living in the Christchurch City region, with a 2% increase in children identifying as Māori, 1% increase identifying as Pasifika, 5% increase identifying as Asian and an 8% decrease identifying as European (Statistics New Zealand, 2018). Subsequent research should consider the growing diversity of New Zealand schools and ensure they take a considered approach that maximises the opportunity for a diverse range of participants.

Christchurch is a unique city in New Zealand. It the past decade it has experienced several traumatic events contributing to the unique perspective of Cantabrians. Chapter one explained many of the contributing factors to the Canterbury regions, of which included the Canterbury earthquakes and mosque attacks. Trapped in medical centres around Christchurch, the earthquakes caused a lack of access to essential, lifesaving medical

information (Ardagh et al., 2012). This lack of access fostered a fertile information-sharing environment that demanded revolutionary change to the way information was stored, shared and managed. As a result, initiatives such as HealthOne and Mana Ake were established, and Canterbury became an area that was subject to more progressive DHB data-sharing initiatives (Canterbury Clinical Network, 2020; HealthOne, 2018). This environment provided an excellent area to start the discussion regarding a DSHISS.

Mixed methods methodology comes with significant, yet manageable limitations. Historically, the concurrent use of qualitative and quantitative research methods had been viewed as conflicting due to the opposing assumptions that underpin both methods (Creswell, 2009). This research utilised both methods and allowed the quantitative results to create tools that linked those results to discussion points that helped develop the qualitative component. This procedure enabled an explanatory sequential mixed method design. Chapter three discussed these methods and the rationale for them in greater detail. A central critique of mixed methods research is the lack of adequate guidelines on how to integrate qualitative and quantitative according to best practice (Venkatesh et al., 2013). Following guidance from Creswell (2015), findings from the questionnaire in phase 2A and 3A were utilised to elicit greater detail of perceptions in the following focus groups. This allowed for the integration of data in an explanatory manner, where the quantitative findings were able to lay the initial foundation to the discussion while allowing the qualitative findings to build on that foundation offering further insight to teacher and parent perceptions of student health information sharing.

More generally, the findings of this research can only represent the current digital culture within a region of New Zealand. The rapidly revolutionary and evolutionary nature of IT, along with the almost polarising access to technology systems across the world and different cultural norms merged in these systems, could mean different levels of ability to manage risk and utilise benefits of sharing health information. With time there will be possibly more or less risk of sharing student health information, more or less benefits, and what may be imaginable today, may be obsolete tomorrow. Similar as technology has evolved so have people's attitudes towards it. The role of technology has become normalised in the 21st century, with younger generations displaying more positive attitudes to technology and data sharing than their older counterparts (Miltgen & Peyrat-Guillard, 2014). As Heraclitus, a Greek philosopher said, *"change is the only constant thing in this world".* Thus, this work can only reflect the current IT environment and general attitudes of individuals in New Zealand.

7.6. A personal reflection on focus groups and findings

As with any controversial initiative, the possibility of a DSHISS engages some core concerns from those whose information (or their child's information in this case) is shared. The back and forth discussion from participants about the benefits and risks, whether they outweighed one or the other, was expected. This discussion, however, did not end in a stalemate, with parents and teachers being staunchly for or opposed, instead, participants were able to see the potential of a DSHISS and actively engaged in brainstorming potential solutions to these concerns. They were empowered to imagine an environment that would integrate the health and education sectors, visualise information moving freely and with minimal risk. Parents and teachers did not merely want to share their beliefs, but work through their concerns,

taking strengths-based and solution-driven approach. The creativity and practicality participants displayed, highlighted the absolute necessity to including the grass-roots players to the discussion early in the development of a DSHISS.

Another unexpected finding was the discussion of the differing expectations of health and education professionals, and how health and well-being are incorporated into the education sector. The higher levels of health concerns in children with below-average oral language ability are concerning and demonstrate the current practices in health and early education are not managing the health or impacts of health on education adequately. As a result, demand for integrated, multi-disciplinary intervention and support is increasing at varying speeds.

All schools included in phase 2 and 3 were experiencing the need for greater health and well-being integration, with this need coming through in the focus groups. However, one of the three schools have been catapulted into this space much quicker than the others. This school has experienced a complete rebuild due to the 2010-2011 earthquakes and took the opportunity to integrate more social and mental well-being into their school ethos. This ethos also acknowledges the importance of collaborative practice, where parents, teacher, school and other organisation work together for the child and in the child's best interests. The ethos of this particular school highlights the evolution of education within New Zealand and the changing roles of teachers and schools within their communities. Schools are becoming increasingly pivotal in communities, providing more than standard academic instruction (Lewallen et al., 2015). It brings together individuals from different backgrounds, with different specialities, to work collaboratively toward a common goal; improving the well-being and success of the student and their whānau.

7.7. Future research directions

This research began the conversation of a DSHISS as a facilitator to improve well-being and learning within New Zealand schools. However, there is more work to be done before any implementation. As mentioned in the previous section, this research did not extend past educators and parents. The introduction of a DSHISS may see GPs workload increase, especially in the implementation of the system which is a particular concern due to the limited length of the appointment times and the current GP shortage in New Zealand (Wilson, 2019). GPs must be considered as vital players in the successful implementation of a DSHISS as they will have a role in sharing this valuable and sensitive information. These health professionals will also bring a unique perspective to the implementation of a DSHISS, bringing their own set of values, expertise and concerns that must be incorporated and considered.

There is also an opportunity for information to be shared bi-directionally. Mana Ake leaders are considering the implications of bi-directional data sharing where teachers can share information with GPs with whānau consent (C. Shepherd, Project lead for Mana Ake, Personal Communication, June 12, 2019). The consideration of bi-directional sharing acknowledges the knowledge and essential role teachers have in being able to provide detailed, useful information about their students' well-being. To fully understand the opportunity of bi-directional information sharing between health and education, further academic input to is required.

There is a need to extend the study to include a higher number of education professionals, parents to improve the representativeness of the findings. Extending the research to include more representative samples of men (as both educators and parents) and greater diversity, particularly those who identify as Pasifika or Asian, will improve the understanding of attitudes across genders and culture. In the extension of the research, it may be appropriate to include an example of a tiered system suggested in this research, so that participants have a clearer picture of how the DSHISS could work, along with a clearer understanding of how the system could impact them. When research included greater diversity and representation of attitudes, it would be appropriate to pilot a tiered DSHISS in various schools across the region or the country before any nationwide implementation. Another factor that requires consideration if the information was to be shared with schools is when do children get a voice? Currently, Gillick competence[13] determines whether a child or adolescent can give informed consent (Griffith, 2016; Hunter & Pierscionek, 2007; McLean, 2000). However, future research must consider the perspectives of children and adolescents at different ages, especially for access to more sensitive information, such as mental health, sexual health and information around puberty and menstruation.

Another area that deserves further work is scientific research into the growing need for integration of health and well-being in New Zealand schools. Research in this area is limited to community-based schools developed mostly in the USA (Dryfoos & Maguire, 2019). Further work needs to consider the different community needs and culture of New Zealand,

[13] Gillick competence is awarded to children under 16 years of age who have sufficient intelligence to understand the nature and implication of a medical procedure or treatment. This gives them the legal right to give or withdraw consent for medical procedures or treatment (Griffith, 2016).

along with how to best integrate health and well-being into New Zealand's education sector for better education and health outcomes. This future research could also consider the potential for a DSHISS to be not only utilised for individual-based intervention, but for population-based research and intervention along with helping to inform public policy. Consideration into the impacts for children who are managing health concerns despite their academic outcomes also needs to be done. There may be an impact on all students with health concerns is a DSHISS was to be implemented regardless of their academic success so far. These impacts may also be less about improving academic success, and more about increasing social factors at school, such as school enjoyment and sense of belonging. Future work also needs to discuss the legal, ethical and consensual barrier to information sharing. These frameworks need to be up to date in order to keep the public safe without limiting research and development. This work must be ongoing and dynamic as technology develops and the reliance on technology and opportunities for intervention based on shared information increase.

Chapter Eight Conclusion

A significant number of children in New Zealand are experiencing health and well-being concerns that are impacting their ability to concentrate and learn. To support children experiencing these concerns, teachers and schools need to be better aware of these concerns, and better equipped to support children in the classroom. A DSHISS has the potential to facilitate this awareness and enable teachers and schools to take a child-centric holistic approach that collaborates with whānau and outside organisations. For a DSHISS to be fully capable, those key stakeholders who would use the system at the grassroots level must support its implementation.

In the development of a DSHISS, it is vital to understand the attitudes of key stakeholders about the risks of a DSHISS and actively consider any solutions or implementation focused suggestions. Including key players in the development and implementation, phases are crucial to the system being accepted by those who will be using or impact by it. Careful thought to the diversity of key players such as educators, parents and health professionals, is needed in future research. This diversity will consider the different job, cultural and gender-specific attitudes vital to the implementation and success of a DSHISS. Development of a DSHISS will need input from varying professionals alongside those key stakeholders. Legal input from the PC will ensure proper legislation is followed, research from health and education to ensure the information shared is evidence-based. At the same time, user interface development will require input from educators and health professionals. A DSHISS will bring professionals from a multitude of different sectors together with the explicit purpose of giving New Zealand's children the absolute best start to maximising their well-being and academic potential. This gift will hold them in good stead for their future.

It is important to note that a DSHISS will not magically remedy the impact of health on child development, literacy and learning. It acts as a safety net and requires organisations, governments and people to seize the opportunity it represents. The system relies on resources being re-positioned to fully utilise the shared information, allowing for effective early intervention in our education sector. This intervention requires a coordinated approach that includes both health and educational specialists working within an integrated whole-child model and can unite will already establish initiatives. The system will sit alongside the changing roles of educators and the need for greater multi-disciplinary, community-inclusive schooling as it begins braiding the rivers of health and education together for positive outcomes for New Zealand's greatest taonga, our tamariki.

"Poipoia te kakano kia puawai"

"Nurture the seed and it will blossom"

– Māori whakataukī (proverb)

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Appendix A – Legislative Information

Appendix A.1 – Ten guiding principles for data collection, storage, sharing and use to ensure security and confidentiality

1. Legitimate public health purposes e.g. prevent or promote though research, surveillance, assessment of health needs, development of policy and responding to emergencies in public health
2. Minimum information necessary. Minimise the identifiability of the data where possible.
3. Privacy and security standards. Ensure that policies and practice is in place to monitor data security, e.g. Privacy officer to maintain unbiased connection that's priority is maintaining the privacy of the data.
4. The rights of individuals and communities. Individuals and community groups must be respected in gathering and storing their data to minimize burden.
5. Data Quality. Data quality should be monitored at all levels of data collection, storage and analyse to ensure that policies developed are based on good data.
6. Data dissemination to relevant stakeholders. Transparency towards stakeholders in how the data is collect and used and for what purpose. Should not impose new burdens on any population.
7. Data use agreements. Agreements made to define the use, scope and specific data shared. When identifiable data used provisions for securing data must be agreed to.
8. Security measures. The data must be maintained in a physically secure environment regardless of it form (paper/electronic).
9. Minimum number of individuals and entities granted access. Particularly for identifiable data.
10. Stewardship and Trust. If the data is collected those using the data are responsible to ensure that the data is used proactively and securely.

Adapted from Lee and Gostin (2009)

Appendix A.2 – Information Privacy Principles from the Privacy Act 1993

1. *Purpose of collection of personal information.* Collection of information must be for a lawful purpose and is necessary for that purpose.
2. *Source of personal information.* An agency must collect directly from the individual concerned, unless for example the information is publicly available, if the individual concerned has authorised collection of information from someone else, the non-compliance would not prejudice the interests of the individual concerned, that non-compliance is necessary to avoid prejudice or is concerned with law enforcement.
3. *Collection of information from subject.* An agency must be transparent when collecting information directly from an individual by informing the fact and purpose that information is collected, the intended recipients, the name of the agency collecting and storing the information, if the collection is authorised or required under law, the consequences if the information is not provided, and the rights of access and correction to personal information.
4. *Manner of collection of personal information.* Personal information cannot be collected by unlawful means, or any means that are unfair or intrude to an unreasonable extent on personal affairs of the individual concerned.
5. *Storage and security of personal information.* An agency that holds personal information must ensure the information is protected against loss and misuse of that information.
6. *Access to personal information.* The individual concerned can have access to their information and to obtain whether the agency holds any personal information.
7. *Correction of personal information.* The individual concerned is entitled to request a correction to the information or to request an attachment to the information with a statement of the correction sought but not made.
8. *Accuracy, etc., of personal information to be checked before use.* Agencies that hold personal information are responsible to ensure the information is accurate, up to date, complete, relevant and not misleading.
9. *Agency not to keep personal information for any longer than necessary.* Information collected must not be kept for any longer than is required.
10. *Limits on use of personal information.* The information will not be used for any other purpose apart from the stated purpose unless for example, the information is publicly available, authorisation has been given by the individual, it is concerned with law enforcement, public or personal safety, or the information is non-identifiable.
11. *Limits on disclosure of personal information.* Personal Information shall not be disclosed unless for example the information is publicly available, is to or authorised by the individual concerned, it is concerned with law enforcement, is concerned with personal or public safety, or the information is non-identifiable.
12. *Unique Identifiers*. Unique Identifiers shall not be assigned and used unless it is necessary to enable the agency to carry out its function efficiently

Adapted from "Privacy Act 1993")

Appendix A.3 – Health Information Privacy Code

1. Health information must only be collected when:
   - The collection is for a lawful purpose, connected with what the agency does, and
   - It is necessary to collect the information for that purpose

2. Health information must usually be collected from the person the information is about. But sometimes it is all right to collect information from other people instead - for instance, when:
   - Getting it from the person concerned would undermine the purpose of the collection
   - It's necessary so a public sector body can uphold or enforce the law
   - The person concerned authorises collection from someone else

3. When a health agency collects health information from the person the information is about, it has to take reasonable steps to make sure that person knows things like:
   - Why it is being collected?
   - Who will get the information?
   - Whether the person *has* to give the information or whether this is voluntary
   - What will happen if the information isn't provided?

   Sometimes there are good reasons for not letting a person know about the collection, for example, if it would undermine the purpose of the collection, or it's just not possible to tell the person.

4. Health information must not be collected by unlawful means or by means that are unfair or unreasonably intrusive in the circumstances.

5. It's impossible to stop all mistakes. But health agencies must ensure that there are **reasonable** safeguards in place to prevent loss, misuse or disclosure of health information.

6. People usually have a right to ask for access to health information that identifies them. However, sometimes, health agencies can refuse to give access to information, for instance because giving the information would:
   - endanger a person's safety
   - prevent detection and investigation of criminal offences
   - involve an unwarranted breach of someone else's privacy.

7. People have a right to ask health agencies to correct health information about themselves, if they think it is wrong. If the health agency does not want to correct the information, it does not usually have to. But people can ask the health agency to add *their* views about what the correct information is.

8. Before it uses or discloses health information a health agency must take reasonable steps to check that information is accurate, complete, relevant, up to date and not misleading.

9. A health agency that holds health information must not keep that information for longer than is necessary for the purposes for which the information may be lawfully used.

10. Health agencies must use health information for the same purpose for which they collected that information. Other uses are occasionally permitted (for example because this is necessary to enforce the law, or the use is directly related to the purpose for which the agency got the information).

11. Health agencies can only disclose health information in limited circumstances. One example is where another law requires them to disclose the information. Also, a health agency can disclose information if it reasonably believes, for example, that
    - disclosure is one of the purposes for which the agency got the information
    - disclosure is necessary to uphold or enforce the law
    - disclosure is necessary for court proceedings
    - the person concerned authorised the disclosure
    - the information is going to be used in a form that does not identify the person concerned.

12. Some agencies give people a "unique identifier" instead of using their name. Examples are a driver's licence number, a student ID number, or an IRD number. A health agency cannot use the unique identifier given to a person by another agency. People are not required to disclose their unique identifier unless this is one of the purposes for which the unique identifier was set up (or directly related to those purposes).

Adapted from Office of the Privacy Commissioner (n.d.-a)

Appendix A.4 – NZDFF Guiding Principles (to Information Sharing)

Value	**New Zealand should use data to drive economic and social value and create a competitive advantage. To achieve this, we should:** • treat data as a strategic asset • encourage collaboration and sharing • support creativity and innovation • Promote our unique data-use ecosystem in New Zealand and overseas.
Inclusion	**All parts of New Zealand society should have the opportunity to benefit from data use.** • We should support all New Zealanders, communities and businesses to adapt and thrive in the new data environment.
Trust	**Data management in New Zealand should build trust and confidence in our institutions.** • Transparency and openness should form key foundations on which we build trust and enhance understanding about what data is held, and how data is managed and used. • Privacy and security are fundamental values that should be built into data frameworks and the full data life cycle. • Data collectors, custodians and users should be accountable for responsible stewardship and should exercise a duty of care.
Control	**Individuals should have greater control over the use of data about them.** • Individuals should be better able to determine the level of privacy they desire based on improved insight into how their personal data is processed and used. • Informed consent should be simple and easy to understand. • Individuals should have enhanced rights to correction and the right to opt out.

Adapted from New Zealand Data Futures Forum (2017)

Appendix B – Ethics Documentation

Appendix B.1 – Ethics Acceptance (2016/21/ERHEC)

UNIVERSITY OF CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

HUMAN ETHICS COMMITTEE

Secretary, Rebecca Robinson
Telephone: +64 03 364 2987, Extn 45588
Email: human-ethics@canterbury.ac.nz

Ref: 2016/21/ERHEC

1 June 2016

Professor Gail Gillon
College of Education, Health & Human Development
UNIVERSITY OF CANTERBURY

Dear Gail,

The Educational Research Human Ethics Committee is pleased to inform you that your research proposal "Eke Pānui, Ake Tamaiti: Braiding Health and Education Services to Ensure Early Literacy Success and Healthy Well-being for Vulnerable Children" has been granted ethical approval at their meeting on 25/5/2016.

However, this approval is subject to the provision of the following:

- *In the Consent Forms and Information Sheets, please widen "mum and/or dad" to include "caregiver" or similar.*
- *Regarding the phrase "your child has been selected", this could possibly be rephrased to explain that the school is part of the programme and the child has been identified as having additional needs.*
- *Please note that approval is for phase one of the study only (2016). The Committee recommends that the second phase (2017) be submitted as a separate application as this requires further intervention and the Committee would require further elaboration on the risks of these interventions.*

Please forward these changes to the Secretary for review and final approval.

If you have any questions regarding the above comments please don't hesitate to contact me.

Yours sincerely

'p R. Robinson

Patrick Shepherd
Chair
Educational Research Human Ethics Committee

Please note that ethical approval relates only to the ethical elements of the relationship between the researcher, research participants and other stakeholders. The granting of approval by the Educational Research Human Ethics Committee should not be interpreted as comment on the methodology, legality, value or any other matters relating to this research.

F E S

UNIVERSITY OF CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

HUMAN ETHICS COMMITTEE

Secretary, Rebecca Robinson
Telephone: +64 03 369 4588, Extn 94588
Email: human-ethics@canterbury.ac.nz

Ref: 2016/64/ERHEC

14 December 2016

Professor Gail Gillon
College of Education, Health and Human Development
UNIVERSITY OF CANTERBURY

Dear Gail

Thank you for providing the revised documents in support of your application to the Educational Research Human Ethics Committee. I am very pleased to inform you that your research proposal "Eke Pānui, Ake Tamaiti: Braiding Health and Education Services to Ensure Early Literacy Success and Healthy Well-being for Vulnerable Children (2)" has been granted ethical approval.

Please note that this approval is subject to the incorporation of the amendments you have provided in your email of 12th December 2016.

Should circumstances relevant to this current application change you are required to reapply for ethical approval.

If you have any questions regarding this approval, please let me know.

We wish you well for your research.

Yours sincerely

pp R. Robinson

Patrick Shepherd
Chair
Educational Research Human Ethics Committee

Please note that ethical approval relates only to the ethical elements of the relationship between the researcher, research participants and other stakeholders. The granting of approval by the Educational Research Human Ethics Committee should not be interpreted as comment on the methodology, legality, value or any other matters relating to this research.

F E S

Appendix B.2 – Ethics Acceptance (2017/50/ERHEC)

UNIVERSITY OF CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

HUMAN ETHICS COMMITTEE

Secretary, Rebecca Robinson
Telephone: +64 03 369 4588, Extn 94588
Email: human-ethics@canterbury.ac.nz

Ref: 2017/50/ERHEC

16 January 2018

Nikita Gregory
School of Health Sciences
UNIVERSITY OF CANTERBURY

Dear Nikita

Thank you for providing the revised documents in support of your application to the Educational Research Human Ethics Committee. I am very pleased to inform you that your research proposal **"**Sharing Health Information with Schools to Improve Achievement - Perceptions of Parents and Teachers" has been granted ethical approval.

Please note that this approval is subject to the incorporation of the amendments you have provided in your emails of 22nd December 2017 and 12th and 16th January 2018.

Should circumstances relevant to this current application change you are required to reapply for ethical approval.

If you have any questions regarding this approval, please let me know.

We wish you well for your research.

Yours sincerely

pp R. Robinson

Dr Patrick Shepherd
Chair
Educational Research Human Ethics Committee

Please note that ethical approval relates only to the ethical elements of the relationship between the researcher, research participants and other stakeholders. The granting of approval by the Educational Research Human Ethics Committee should not be interpreted as comment on the methodology, legality, value or any other matters relating to this research.

F E S

Appendix C – Phase One Documents

Appendix C.1 – Parents' Consent Form and Information Sheet for ABS intervention

Consent Form for A Better Start Intervention

College of Education, Health and Human Development

21/02/2017

CONSENT FORM – Parents

Research project title: A Better Start: E Tipu e Rea
Principal Investigator: Professor Gail Gillon

I have read and understood the description and information on this project, a full explanation has been given to me and I have had the opportunity to ask questions. On this basis I agree to allow my child (name) _____ to participate.

I understand I have the right to withdraw my child from the project at any time. If I choose to withdraw my child, the researcher will do their best to remove any of the information relating to me from the project.

I understand that all information gathered will be kept confidential to the research team and that published or reported results will not identify my child. I understand that participation in this research will be confidential, however mine and my child's information will be known to the researcher, so anonymity cannot be provided.

I am aware that involvement in this study requires me to attend a workshop and complete a questionnaire.

I understand that all data collected will be kept in a locked and secured facility and password protected in electronic form and will be destroyed after five years. I accept there is no known risk to participation in this project.

I consent to publication of the results of the project with the understanding that confidentiality will be preserved.

I understand I am able to receive a report of the findings of this study once completed. This will be provided to me via the email address below.

I note that the project has been reviewed and approved by the University of Canterbury Human Ethics Committee and any complaints can be directed to the Chair, University of Canterbury Educational Research Human Ethics Committee.

Your name (please print): …….

Signature: ..... Date: .....

Best contact phone number: .....

Address: .....

Email: .....

Your child's ethnicity: .....

My contact details are as follows:
Principal Investigator – A Better Start: E Tipu e Rea (Literacy and Learning)
Professor Gail Gillon
Email: gail.gillon@canterbury.ac.nz
Phone: (03) 343 7724

If you would like help with understanding this letter, please tell your child's classroom teacher, or contact:
Sonja Macfarlane (Ngāi Tahu)
Email: Sonja.macfarlane@canterbury.ac.nz
Phone: 0274579960
Tufulasi Taleni
Email: Tufulasi.taleni@canterbury.ac.nz
Phone: (03) 369 3389

Information Sheet for A Better Start Intervention

College of Education, Health and Human Development

21/02/17

UNIVERSITY OF CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

INFORMATON SHEET – Parents

Research project title: A Better Start: E Tipu e Rea
Principal Investigator: Professor Gail Gillon

Your child's school is involved in a research project run by Professor Gail Gillon from the University of Canterbury, looking at improving the early literacy and health outcomes for children in their first year of school. This project forms one strand of the nationwide National Science Challenge funded by the Ministry of Business and Innovation.

The research is designed to investigate the effectiveness of an intervention designed to support children's reading development. This intervention will be called Eke Pānui, Ake Tamaiti (a Māori concept: "Embark reading success; grow the child's success").

This study will involve working with your child during their first two years of school, to track their progress as they settle in, and participate in a classroom-based reading programme. This monitoring will consist of the collection of information on your child's language and reading development at several points during the 2017 and 2018 school years. Some of this information will be collected by their teacher and some of this information will be collected by trained Research Assistants working on this project. If your child is growing up with two or more languages, you may be invited to share your experiences of their language learning and the digital world.

In addition, your involvement will consist of your participation in a series of two workshops on supporting your child's early reading development. These workshops will occur in Term 2, lasting for approximately 1 hour. Involvement in this project will also include completing a questionnaire with one of our research team on your child's reading and your home literacy environment. To thank you for your participation, a small koha of some picture books will be provided during the workshops.

Your name, your child's name and the name of their school will not be used in the research and all data collected will be kept in secure location. Participation in this research will be confidential, however your child's information will be known to the researcher, so anonymity

cannot be provided. There are no known risks to being part of this study. Participation is voluntary and you or your child can withdraw from the research at any time.

A summary of the results will be available to you once they have been analysed and I am happy to answer any questions you have about any part of this research study. Some of the data collected in this study will be listened to or viewed and transcribed by Research Assistants and/or PhD students involved with the study. They will sign their own confidentiality agreements to ensure you and your child's information is kept safe.
The data collected from this research will be published in international and national peer-reviewed journals. PhD theses that examine some aspect of the project will be uploaded to the UC library database. Whenever the data is published, it will be published in summarised form with no individual name or centre/school identified. If case data is used, then pseudonyms will be used to avoid identification.

This project has received ethical approval from the University of Canterbury Educational Research Human Ethics Committee. Complaints may be addressed to:
The Chair, Educational Research Human Ethics Committee, University of Canterbury, Private Bag 4800, Christchurch. Email: human-ethics@canterbury.ac.nz.

Please contact me if you have any questions. My contact details are as follows:
Principal Investigator – A Better Start: E Tipu e Rea (Literacy and Learning)
Professor Gail Gillon
Email: gail.gillon@canterbury.ac.nz
Phone: (03) 343 7724

If you would like help with understanding this letter, please tell your child's classroom teacher, or contact:
Sonja Macfarlane (Ngāi Tahu)
Email: Sonja.macfarlane@canterbury.ac.nz
Phone: 0274579960
Tufulasi Taleni
Email: Tufulasi.taleni@canterbury.ac.nz
Phone: (03) 369 3389

Please sign the attached consent form if you understand and agree to you and your child taking part

in the study, and return it to your child's classroom teacher by
_____.

Appendix C.2 – Child's Consent Form and Information Sheet for ABS intervention

College of Education, Health and Human Development

UNIVERSITY OF CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

CONSENT FORM – Children
(to be read to child by adult)

Research project title: A Better Start: E Tipu e Rea
Principal Investigator: Professor Gail Gillon

My mum/dad/caregiver has told me about your project.
I am happy to be part of a study looking at my reading. I know this will mean I will have to play some reading games. I know that [Researcher's name] will talk to my mum/dad/caregiver and my teacher about reading too.

I know that information collected about me will not be told to anyone else and will be stored away in a safe place. My name, my parent/caregiver's name and the name of my early childcare centre will not be used. All information will be deleted after the project has been written up. My parent/caregivers will receive a small report about the project.

I understand that I can change my mind about being in this project and no-one will mind.
I know that if I have any questions, I can ask my mum/dad/caregiver.

Child's name (please print): …….

Date: .....

[Note: The parents/caregivers will also receive a full information sheet and will be required to complete a consent form as well before the child can take part in this research]

College of Education, Health and Human Development

14/3/17

INFORMATION SHEET – Children

Research project title: A Better Start: E Tipu e Rea
Principal Investigator: Professor Gail Gillon

[Researcher's name] is doing a project at the university. She/he is going to work with your teacher and Mum/Dad/caregiver to help you with your reading and learn more about ways to help other children learn to read, too.

[Researcher's name] will play some games with you to find out about your reading. S/he will also chat to other people who work with you to see what they think will help with learning to read.

When [Researcher's name] writes things down about you, you will be given a code name so that no-one will know your name, your teacher's name, or the name of your school. All the information collected about you will be kept locked away, and will be destroyed after [Researcher's name] has finished using it.

Your Mum/Dad/caregiver and teacher has also been asked to help. If you have any questions, you can talk to your Mum/Dad/caregiver or to [Researcher's name]. If you change your mind about being in the project, that's fine, too. All you have to do is to tell your mum/dad/caregiver or [Researcher's name].

Thank you for helping with the project.
[Researcher's name]

Appendix C.3 – Parents' Information Sheet for Whānau Questionnaire and Whānau Questionnaire

Eke pānui, ake tamaiti
Set sail on reading, uplift the child

Whānau/Family/Aiga/Caregiver Questionnaire

INFORMATION SHEET

Tēnā koe; Talofa lava; Greetings to you.

Thank you once again for agreeing to complete this questionnaire. Your involvement is central to the success of this project; it is valued and very much appreciated.

Completing the questionnaire

WHY? To find out more about your child's reading and development to support the '***A Better Start***' literacy programme that is happening in your child's class.

HOW? There are **two options** available to you:

1. Complete the **online** version, by clicking on the link you will receive in an email (this will only be available if the school has your email address recorded).

OR

2. Complete the **paper copy** version that is attached to this Information Sheet, and return it to school.

You can come to a **drop-in session** at your child's school if you would like support to complete the questionnaire. You will be able to ask questions and talk with others:

✓ [redacted]
✓ [redacted]
✓ [redacted]

You can ask for a **one-on-one individual session** with a member of the project (contact details are listed below).

WHEN? The questionnaires need to be **completed by Friday 7 July 2017**

Ngā mihi mahana ki a koe; Fa'afetai tele ma ia manuia; Warmest regards to you.
Thank you once again for completing this questionnaire.

Contacts:

[redacted]

NB: dark grey boxes are redactions of identifiable information

Eke pānui, ake tamaiti
Set sail on reading, uplift the child

Whānau/Family/Aiga/Caregiver Questionnaire

Tēnā koe; Talofa lava; Greetings to you.

Thank you for agreeing to complete this questionnaire. We are very interested in your thoughts, ideas and opinions about reading and learning. The questions are set out in four sections. There are no wrong answers!

Name: _____

Address: _____

_____

Contact phone #:_____

Name of your tamaiti /child / tama: _____

Gender: Girl ☐ Boy ☐

Date of birth: _____

Ethnicity:

New Zealand Māori	☐	iwi affiliation(s) _____ _____
New Zealand Pākehā/European	☐	
Samoan	☐	
Cook Island Māori	☐	
Tongan	☐	
Fijian	☐	
Niuean	☐	
Tokelauan	☐	
Australian	☐	
Asian	☐	Please specify_____
African	☐	Please specify_____
Other	☐	Please specify_____

Relationship to your tama/child:

Mother	☐
Father	☐
Grandmother/Tāua/Kuia/Tina matua	☐
Grandfather/Pōua/Koro/Tama matua	☐
Aunty	☐
Uncle	☐
Whāngai mother/father	☐
Other: _____	

Section One: **Hauora**
Health and wellbeing

Physical health

1. Which word best describes the health of your tamaiti/child/tama?
    a. Excellent
    b. Good
    c. Fair
    d. Poor
2. Have any of the following ever been raised as possible areas of concern for your tamaiti/child/tama? (select any that apply)
    a. Hearing
    b. Vision
    c. Speech
    d. Behaviour
    e. Learning
    f. Movement or mobility
    g. Growth or physical development
    h. Weight
    i. Sleeping patterns
    j. Other (please specify): _____
    k. No concerns (go to Question 4)
3. What type of treatment has your tamaiti/child/tama received?
(select any that apply)
    a. Grommets
    b. Hearing aids
    c. Glasses
    d. Speech and language therapy
    e. Behaviour support
    f. Physical therapy
    g. Occupational therapy
    h. Diet or nutritional advice
    i. Medication(s)
    j. Surgery
    k. Other (please specify): _____
    l. Nothing as yet
4. Which, of these common childhood illnesses has your tamaiti/child/tama had in the last 12 months? (select any that apply)
    a. Non-food allergy / allergies
    b. Food allergy / allergies
    c. Ear aches or infections
    d. Asthma
    e. Chest infections, bronchitis, bronchiolitis, pneumonia
    f. Eczema or dermatitis
    g. Throat infection or tonsillitis
    h. None of the above

5. Has your tamaiti/child/tama ever had any of the following? (select any that apply)
    a. Measles / rubella
    b. Chicken pox
    c. Mumps
    d. Meningitis
    e. Whooping cough
    f. Rheumatic fever
    g. Scarlet fever
    h. None of the above
6. Do you think that a teacher should have **access** to a child's medical/health records?
    a. Yes
    b. No

    Please explain your reason(s) for your choice:

    _____
    _____
7. Do you think that teacher awareness about a child's medical/health information is important to the teaching and learning that happens at school?
    a. Yes
    b. No

    Please explain your reason(s) for your choice:

    _____
    _____
8. Whānau/family/aiga/caregiver consent for a teacher to have access to a child/s medical/health records should be:
    a. automatically given as part of the school enrolment process
    b. given only when a request has been made for health data to be released

Speech, Literacy, Language and Hearing

9. Do you have any concerns about your child's speech, literacy or language - specifically in regards to her/his ability to communicate with others?
    a. No (go to Question 13)
    b. Yes (my concerns are: _____
    _____)
10. Has anyone else e.g. member(s) of your (family/whānau/aiga, teacher, other) had any concerns about your child's speech, literacy or language?
    a. No
    b. Yes (their concerns are:_____
    _____)
11. Have you sought professional support, help and advice to help you manage these concerns?
    a. No (go to Question 13)
    b. Yes
12. What type(s) of professional support, help and advice have you sought?
    a. Health professional (e.g. Plunket nurse, doctor etc.)
    b. Education professional (e.g. teacher, speech language therapist etc.)
    c. Other (please specify:_____)
13. Does your tamaiti/child/tama have a hearing impairment?
    a. Yes
    b. No (go to Question 19)

14. Was this hearing impairment identified at birth or any time before the age of 3 months?
    a. Yes
    b. No
15. If you answered 'no' to Question 14, at what age was the hearing impairment identified? _____
16. What is the degree of hearing loss?
    a. Mild
    b. Moderate
    c. Severe
    d. Profound
17. Does your tamaiti/child/tama use a hearing aid/s or have a cochlear implant? (choose the ones that apply)
    a. No (go to Question 19)
    b. Hearing aids in one ear
    c. Hearing aids in both ears
    d. Cochlear implant in one ear
    e. Cochlear implant in both ears
18. How often does your tamaiti/child/tama wear their hearing aids?
    a. Not very often
    b. Sometimes
    c. Often
    d. All the time

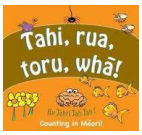
Sleep

19. Does your tamaiti/child/tama usually sleep well throughout the night?
    a. Yes
    b. No
20. What time does your tamaiti/child/tama usually go to sleep during week (school) nights?
    _____
21. What time does your tamaiti/child/tama usually wake up in the morning?
    _____
22. Which of the following apply to your tamaiti/child/tama? (select any that apply)
    a. Has trouble going to sleep
    b. Sometimes has a scary dream that wakes her / him up
    c. Sometimes sleep-walks
    d. Regularly wakes during the night (usual number of times: _____)
    e. Is often sleepy during the day
    f. None of the above

Behaviour

23. Based on your child's behaviour over the past 6 months, how do the following apply?

Statement	Mostly	Sometimes	Hardly ever	Never
a. Is considerate of other people's feelings				
b. Shares and takes turns with other tamariki/children/tamaiti				
c. Is helpful, kind and caring if someone is hurt, upset or unwell				
d. Gets on well with other people				
e. Is generally polite and usually follows adults' requests				
f. Has at least one good friend				
g. Prefers being / playing alone				
h. Seems to worry about things				
i. Is restless or agitated				
j. Has difficulty concentrating				
k. Gets angry / upset easily				



Section Two: **Hononga**
Reading together at home

24. How old was your tamaiti/child/tama when reading together at home started for them?
    a. From birth onwards
    b. 3-6 months
    c. 7-12 months
    d. 1-2 years
    e. 2-3 years
    f. 3-4 years
    g. When they start / started school
25. How often do the following activities happen at home for your tamaiti/child/tama?

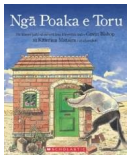
Activity	Often	Sometimes	Hardly ever	Never
a. Story-telling				
b. Singing songs				
c. Talking about your day				
d. Sharing memories: whānau/family/aiga history				
e. Playing word games				
f. Reading signs and labels				
g. Reading books				

26. For your tamaiti/child/tama, how often does reading together at home happen **each week**?
    a. 8 or more times
    b. 5 – 7 times
    c. 2 – 4 times
    d. Once
    e. Never
27. What times of the day are best in your whānau/family/aiga for reading together at home? (select any that apply)
    a. Before school
    b. Straight after school
    c. At bedtime
    d. None of the above
28. Where do the books that are used in your whānau/family/aiga for reading together at home come from?: (select any that apply)
    a. the school
    b. the library
    c. friends and whānau/family/aiga
    d. your own books
    e. none of the above

29. Approximately how many reading together books would you usually have at home?
    a. 10 or more
    b. 5 – 9
    c. 1 – 4
    d. None
30. How important to your whānau/family/aiga is reading together at home?
    a. Extremely important
    b. Reasonably important
    c. Not that important
    d. Not sure

    Please explain:

    _____
    _____
31. When you read together at home with your tamaiti/child/tama, what things do <u>you</u> enjoy most about it? (select any that apply)
    a. The physical closeness
    b. The social / interpersonal aspects
    c. The learning and knowledge gains for your tamaiti/child/tama
    d. The growth in your child's personal confidence
    e. Other: _____



Section Three: **Hinengaro**
Reading practices

32. **How well** does your tamaiti/child/tama do the following during reading and learning together at home?

	Very well	Quite well	Not well	Not yet
a. Sit and engage in the story				
b. Know when the book is the right way up				
c. Turn the page at the right time				
d. Point to (recognise) particular **letters** when asked (e.g. *"Where is the letter 'a'?"*)				
e. Point to and say **letters** without even being asked				
f. Point to and read particular **words** when asked (e.g. *"where is the word 'car'?"*)				
g. Point to and say **words** without even being asked				
h. Know that a **capital letter** starts a new sentence				
i. Know what a **full-stop** does				
j. Read sentences				
k. Recognise her/his own first name				
l. Recognise her/his own surname				
m. Write her/his own first name				
n. Write his/her own surname				

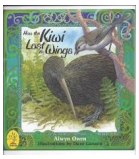
33. **How often** does your tamaiti/child/tama do the following during reading and learning together at home?

	Often	Sometimes	Hardly ever	Never
a. Recognises and/or attempts to make sounds for alphabet letters				
b. Talks and/or asks questions about pictures				

c. Talks and/or asks questions about characters or events				
d. Pretends to read the story in a book that is familiar				
e. Predicts the next word(s) or sentence in a book that is familiar				
f. Reacts to stories in ways that indicate understanding / comprehension				

34. **How often** do these things happen when you are with your tamaiti/child/tama?

	Often	**Sometimes**	**Hardly ever**	**Never**
a. Words (e.g. McDonalds, Farmers, street signs) are pointed out to her/him				
b. Words in the environment (e.g. Weetbix, Warehouse) are recognised and said by her/him				
c. Your tamaiti/child/tama asks about unknown printed words in the environment				
d. You teach the names and/or the sounds of letters of the alphabet				



Section Four: Harikoa
Positive identities

Motivators

35. Do you think your tamaiti/child/tama enjoys being read to?
    a. Yes
    b. No
36. How would you rate your child's interest in reading together?
    a. Very interested
    b. Quite interested
    c. Not very interested
    d. Not at all interested
37. How would you rate your child's interest in reading alone?
    a. Very interested
    b. Quite interested
    c. Not very interested
    d. Not at all interested
38. How many times did your tamaiti/child/tama ask to be read to last week? _____
39. What types of books does your tamaiti/child/tama prefer when **reading together**? (select those that apply)
    a. Books with pictures only
    b. Books with pictures and words
    c. Books with words only
40. How many times did your tamaiti/child/tama engage with a book on their own last week? _____

Language(s): bilingualism

41. The language(s) spoken by your tamaiti/child/tama are:
    a. _____
    b. _____
    c. _____
42. Your child's first language is: _____
43. Your child's strongest/preferred language is: _____
44. The main language spoken by and with whānau /family/aiga at home is: _____
45. If more than one language is spoken at home, during an average week what would you estimate to be the percentages that are spoken to and by your tamaiti/child/tama?
    a. English ____%
    b. Māori ____%
    c. Samoan ____%
    d. Other language __% (Name of the language _____)
46. How important is it to your aiga/family to maintaining multiple languages for your tamaiti/child/tama?
    a. Very important
    b. Quite important
    c. Not that important
    d. Not important at all

47. If your tamaiti/child/tama speaks another language besides English (name this language: _____), how often does she/he do the following in that language?

	Often	Sometimes	Hardly ever	Never
a. Greet and/or farewell people				
b. Introduce themselves to others				
c. Recognise when it is relevant to speak / use the language				
d. Use simple (naming) words to identify particular objects				
e. Use and respond to simple sentences, phrases and instructions				
f. Ask simple questions				
g. Use more complex sentences and phrases				
h. Sing songs, recount proverbs / prayers				
i. Read and understand written words				

Digital media / devices

48. What devices do members of your whānau/family/aiga (including your tamaiti/child/tama) use to access the digital world (internet, social media)? (select any that apply)
    a. Smart phone
    b. Hand held device (e.g. I-pad, tablet)
    c. Laptop / computer at home
    d. Networked computer at work, school or the library
49. How do members of your whānau/family/aiga connect to the digital world (internet / social media)? (select any that apply)
    a. Free wifi
    b. Mobile phone plan
    c. Wifi / Broadband access at home
    d. Wifi / Broadband access at work, school or the library
    e. Other: _____
50. During a typical week at home, approximately how many hours would your tamaiti/child/tama spend on digital media?
    a. More than 5 hours
    b. 3 – 5 hours
    c. 1 – 3 hours
    d. Less than an hour
    e. Never
51. Do you think this amount of time is suitable?
    a. Yes
    b. No
    c. Not sure

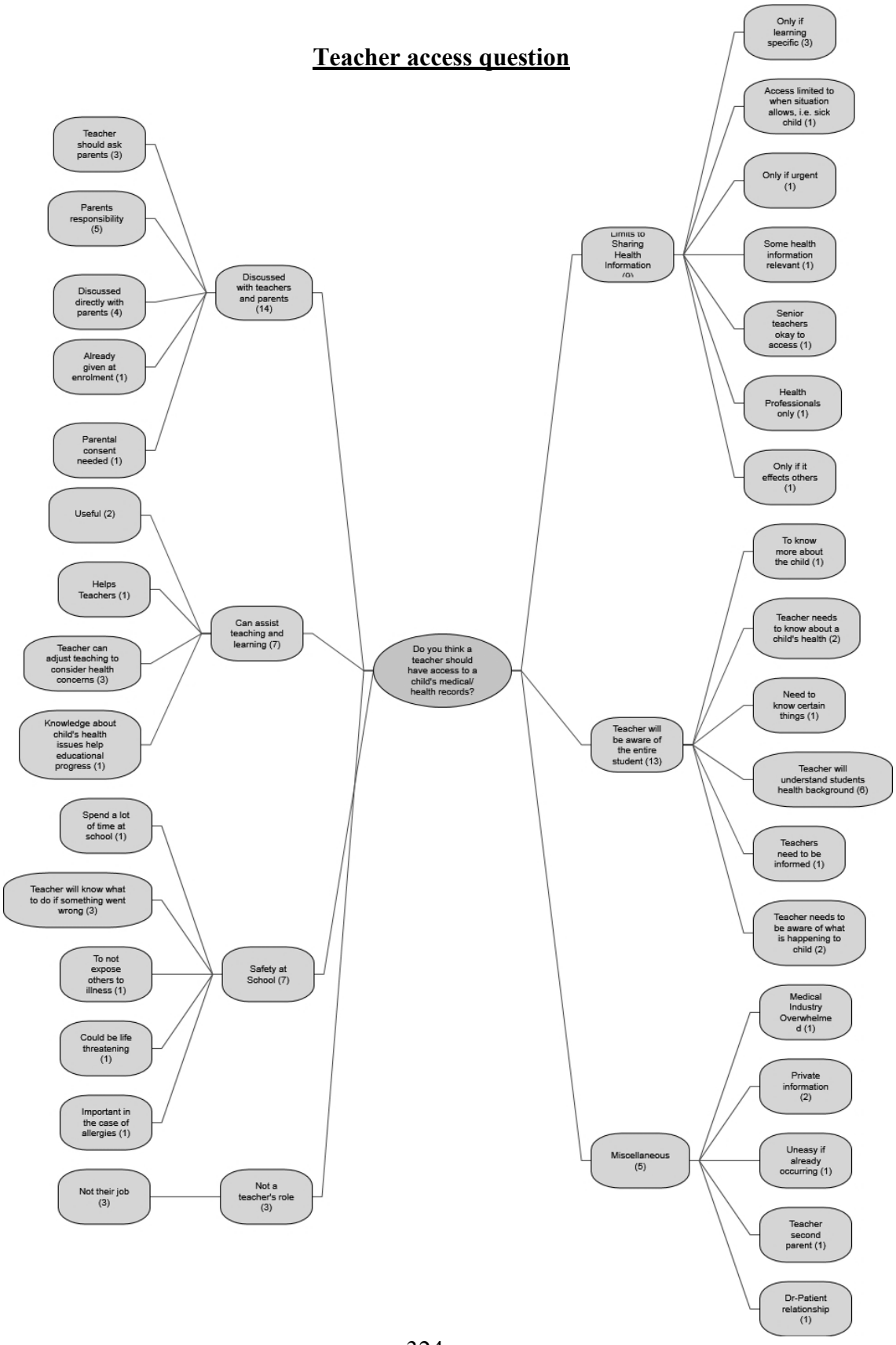
52. How is your child's use of digital devices regulated? (select any that apply)
    a. By having designated times during each day for device use
    b. By having device-free days (e.g. school days)
    c. By having device-free times (e.g. mealtimes, before school, bedtime)
    d. By checking the internet / browser history
    e. By installing a use-monitoring app (e.g. DinnerTime Parental Control, Net Nanny…..)
    f. No strict plan: discussions and decisions are made as and when required
53. When your tamaiti/child/tama is using digital devices at home, how often is time spent on the following?

	Often	Sometimes	Hardly ever	Never
a. Using apps / software that support learning the English language				
b. Using apps / software that support learning another language, e.g. _____				
c. Communicating online with whānau/family/aiga/friends in other locations				
d. Engaging with the school, and any recommended learning resources				
e. Taking photos / videos to support learning and wellbeing				
f. Seeking out new information to support learning and /or wellbeing				

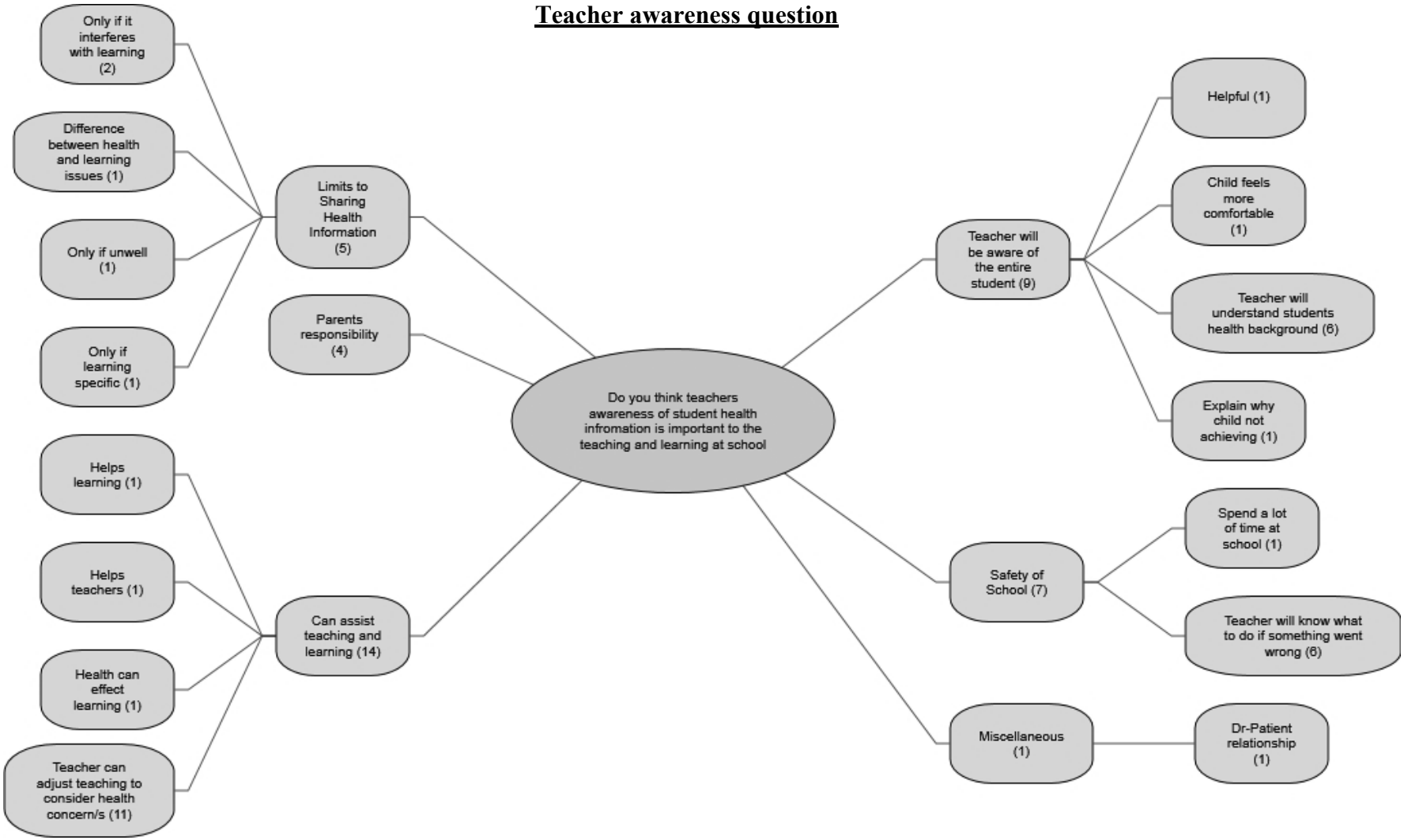
54. What type(s) of digital activities does your tamaiti/child/tama engage in to support learning?
    a. _____
    b. _____
    c. _____
    d. _____
55. What type(s) of digital activities does your tamaiti/child/tama engage in for entertainment?
    a. _____
    b. _____
    c. _____
    d. _____
56. Would you be happy for someone to contact you for further information?
    a. Yes
    b. No

Ngā mihi mahana ki a koe; Fa'afetai tele ma ia manuia; Warmest regards to you.
Thank you for taking the time to complete this questionnaire.

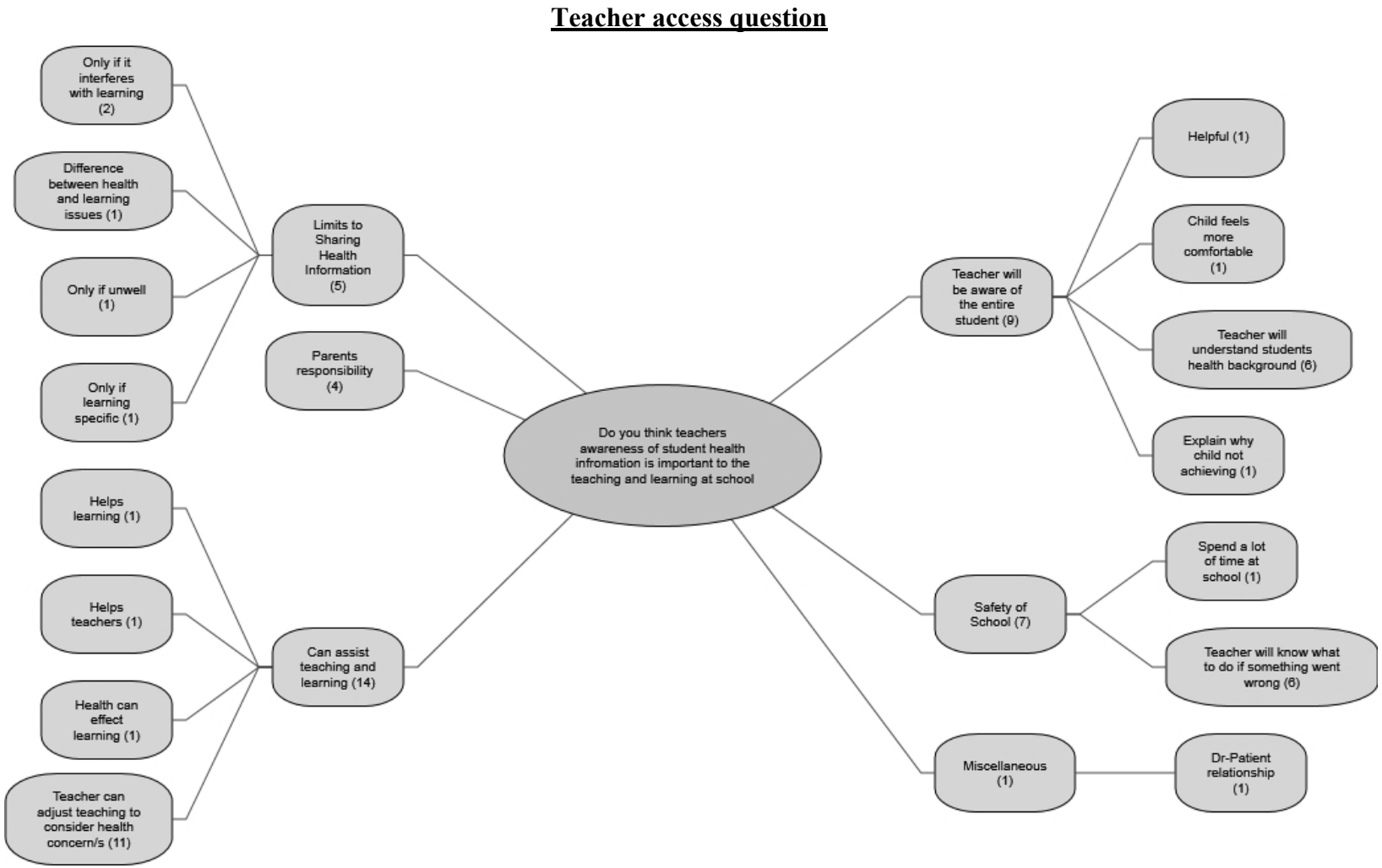
Appendix C.4 – Step Three: Thematic Maps



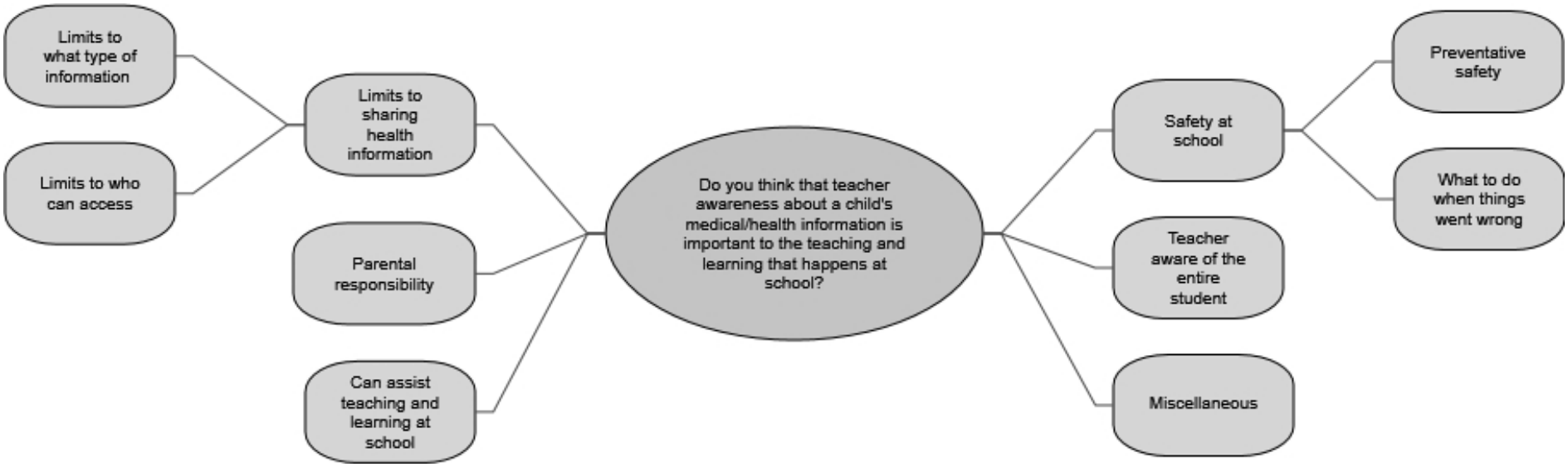
Teacher awareness question



Appendix C.5 – Step Four: Thematic Maps



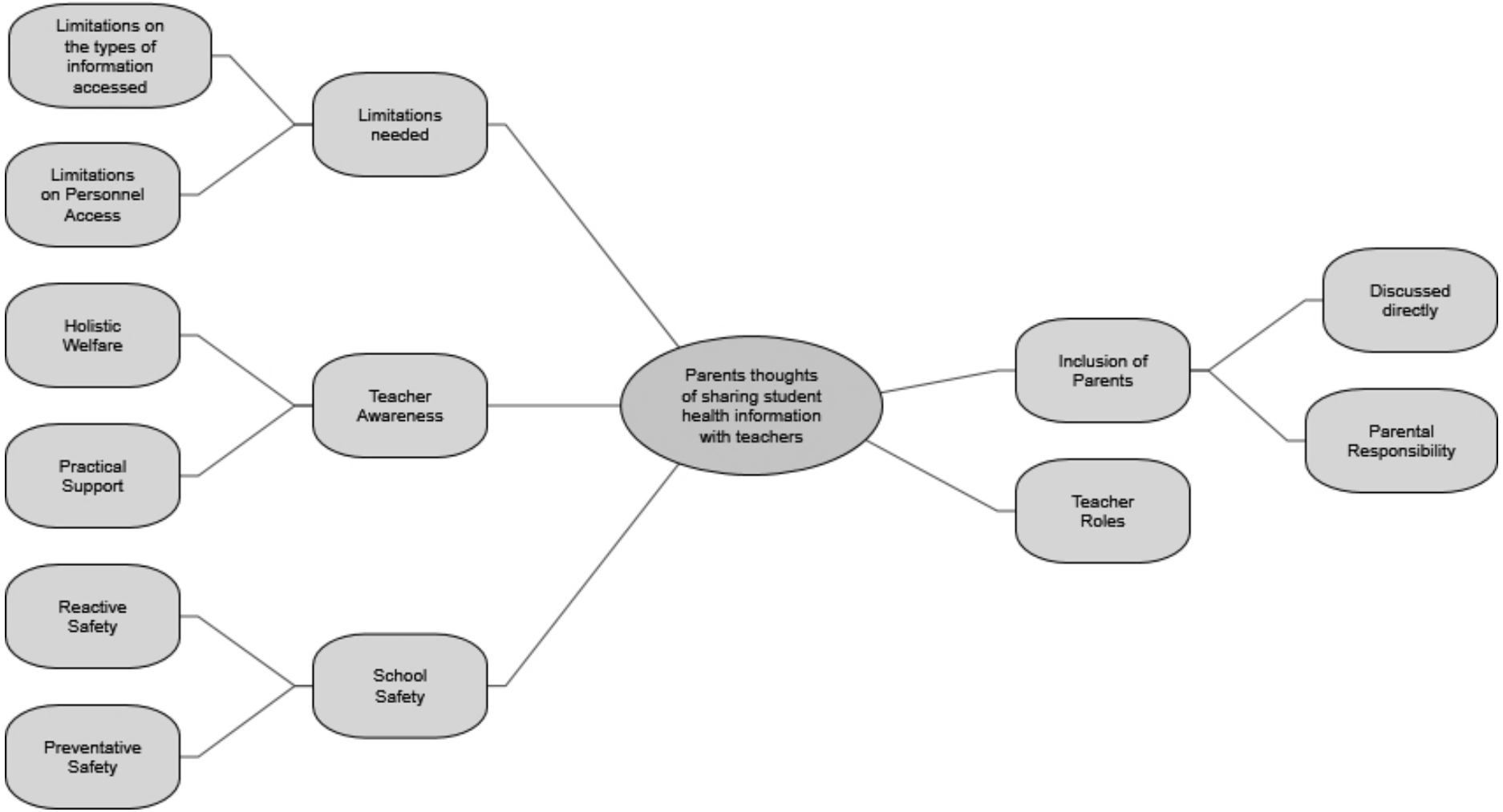
Teacher awareness question



Appendix C.6 – Theme Definitions

- Limits to sharing health information – Limits to what type of information and Limits to who can access
    - This themes discusses the need for limitations on who is able to access information and what particular information is shared with teachers and schools. Highlighted the need for parents to be informed of what information is shared and who can access it.
- Parental responsibility
    - Participants saw parents as having a responsibility to ensure their child's health information was safe and to share the information when necessary. Participants saw this responsibility as a vital role of the parent, and also discussed how there is a need for discussion to occur with teachers.
- Can assist teaching and learning at school
    - Participants saw health information sharing as a way to improve the teaching and learning at school as understanding the health background of students allows for greater practical support from teachers and schools.
- Safety at school – preventative safety and what to do when things went wrong
    - Allows schools and teachers the ability to act quickly in the face of medical emergencies (reactive safety) and minimise the chances of medical incidents in the first place.
- Teacher aware of the entire student
    - Participants saw educators being able to better understand their students in a more holistic sense, and provide holistic support.
- Miscellaneous
    - Codes that did not fit in above themes.

Appendix C.7 – Step Five: Final Thematic Map



Appendix D – Phase Two Documents

Appendix D.1 – Kaiako Consent, Information Sheet and Questionnaire

Study ID:

School of Health Sciences
College of Education, Health and Human Development
University of Canterbury
Private Bag 4800
Christchurch, New Zealand

UC UNIVERSITY OF CANTERBURY
Te Whare Wānanga o Waitaha CHRISTCHURCH NEW ZEALAND

Sharing health information with schools to enhance children's educational outcomes
Consent Form for Questionnaire

Please sign below to indicate that you understand and agree with each statement:

- I have been given a full explanation of this project and have had the opportunity to ask questions.
- I understand what is required of me if I agree to take part in the research.
- I understand that participation is voluntary, and I may withdraw at any time without penalty. Withdrawal of participation will also include the withdrawal of any information I have provided should this remain practically achievable.
- I understand that any information or opinions I provide will be kept confidential to the researcher, Nikita Gregory, and that any published or reported results will not identify the participants or the involved school. I understand that Nikita Gregory's supervisory team may have access to the research database, which has replaced my identifiable data with a study identification number. I understand that the study findings will be presented in a thesis, which is a public document and will be available through the UC Library.
- I understand that all data collected for the study will be kept in locked and secure facilities and/or in password protected electronic form and will be destroyed after 10 years.
- I understand that while anonymity cannot be provided, all identifiable information will be treated confidentially, and protected in password protected computers and locked filing cabinets only accessible by Nikita Gregory. I understand that study IDs will be allocated to further protect my information.
- I understand that I can contact the researcher, Nikita Gregory (nikita.gregory@pg.canterbury.ac.nz), or her supervisory team: Professor Philip Schluter (philip.schluter@canterbury.ac.nz), Professor Gail Gillon (gail.gillon@canterbury.ac.nz) and Associate Professor Brigid McNeill (brigid.mcneill@canterbury.ac.nz) for further information. If I have any complaints, I can contact the Chair of the University of Canterbury Educational Research Human Ethics Committee, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz).
- By signing below, I agree to participate in this research project and understand the above statements.

*Name:*_____ *Signed:*_____ *Date:*_____

I would like to (please tick all that apply)

☐ Go into the draw to win $100 grocery voucher

☐ Be contacted via phone/email as a potential participant in a follow-up focus group related to this questionnaire (any participation in focus groups is voluntary, and every focus group participant will receive a small koha to show our appreciation for their time)

☐ Have a summary of the results emailed to me

If you have ticked any of the above, please provide an email or phone number for Nikita to get in touch

Email /phone number *(for $100 grocery voucher draw, report of findings and/or follow-up focus group)*:

Please return this along with your questionnaire to your child's teacher or school staff member

Study ID:

School of Health Sciences
College of Education, Health and Human Development
University of Canterbury
Private Bag 4800
Christchurch, New Zealand

UNIVERSITY OF CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

Sharing health information with schools to enhance children's educational outcomes – What are your perceptions?
Information Sheet - Questionnaires

About the Study
The purpose of this study is to discover individuals' perceptions and beliefs around sharing a student's health information with teachers and schools. There are two parts to this study. The first part is a questionnaire for parents and teachers asking about their concerns and beliefs around sharing student health information with schools. Part Two is a follow up focus group, for teachers and parents, to discuss the themes that come from the questionnaire in an open environment.

Voluntary Participation, Commitment and Withdrawal
Participation for both parts of the study is optional and you are welcome to take part in none, one or both parts. If you do choose to participate in this part of study, you will be asked to complete a short questionnaire. The questionnaire is likely to take 10-15 minutes. Participation is voluntary, and you have the right to withdraw at any stage without penalty. You may ask for your raw data to be removed at any point and we will do our best to remove all of the information relating to you from the research provided that this remains practically achievable.

Confidentiality and Publishing
Any information or opinions you provide will be kept confidential to the researcher, Nikita Gregory, and that any published or reported results will not identify the participants or involved school. Nikita Gregory's supervisory team may have access to the research database, which will have any identifiable data replaced with a study identification number. Data collected for the study will be kept in locked and secure facilities and/or in password protected electronic form and will be destroyed after 10 years. While anonymity cannot be provided, identifiable information will be confidential, and protected in password protected computers and locked filing cabinets only accessible by Nikita Gregory.

Contact Details
You are welcome to contact Nikita Gregory (nikita.gregory@pg.canterbury.ac.nz), and the supervisory team: Professor Philip Schluter (philip.schluter@canterbury.ac.nz), Professor Gail Gillon (gail.gillon@canterbury.ac.nz) and Associate Professor Brigid McNeill (brigid.mcneill@canterbury.ac.nz) if you have any queries or comments relating to this research. This project has been reviewed and approved by the University of Canterbury Educational Research Human Ethics Committee and participants should address any complaints to The Chair, Educational Research Human Ethics Committee, University of Canterbury, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz).

If you agree to participate in the study, you are asked to complete the consent form and questionnaire, and return it via email to Nikita Gregory (nikita.gregory@pg.canterbury.ac.nz) or using the prepaid envelope provided. Alternatively, you are welcome to return it to your child's teacher.

Study ID:

5) Who would you think should have access to student health information? (tick all that apply)

- ☐ Principal of School
- ☐ Senior Management (Deputy Principal, Head of Year, Dean, Team Leader)
- ☐ Health Staff (Public Health Nurse, School Nurse)
- ☐ Teachers in child's year/team
- ☐ Other: _____
- ☐ Child's classroom teacher
- ☐ Support Staff (Social Workers, Teacher Aides, RTLBs, Counsellor)
- ☐ None
- ☐ No preference

6) Whānau/family/caregiver consent for a kaiako/teacher to have access to a child's health records should be (please tick one):

- ☐ automatically given as part of the school enrolment process
- ☐ given only when a request has been made for health data to be released

Please briefly explain your reason(s) for your choice: _____

7) What role and/or responsibility does a parent have in sharing their child's health information with schools/teachers? (tick all that apply)

- ☐ To allow teachers access to health information that could concern the safety of others at school
- ☐ To ensure teachers have relevant health information regarding students with health concerns
- ☐ To give consent for access to health information
- ☐ To keep a child's health information between the whanau and the doctor
- ☐ Other: _____
- ☐ To ensure their child does not put other children at school at risk of infectious illness
- ☐ To allow teachers access to health information that could concern the child's learning
- ☐ To limit who can access their child's health information
- ☐ To provide teachers with relevant health information

8) What role/responsibility does a teacher have in managing a student's health and health information? (tick all that apply)

- ☐ To understand students' health backgrounds
- ☐ To educate students with what health information is available to them
- ☐ To provide emotional and social support when required
- ☐ To ensure a students' private information is only shared with individuals on a need to know basis
- ☐ To adjust teaching according to students' health background
- ☐ Other: _____
- ☐ To know how to act in a medical incident
- ☐ To be fully aware of any student health concerns
- ☐ To take on the role of a parent during school hours
- ☐ To discuss student health concerns with parents prior to providing support or teaching adjustments
- ☐ To act on the parents' behalf when necessary

Study ID:

9) What role/responsibility does a school have in managing a student's health and health information? (tick all that apply)

- ☐ To provide a safety environment for students
- ☐ To ensure parents are well informed of what sensitive information has been passed on to teachers
- ☐ To minimise infectious illness
- ☐ To ensure the school environment fosters learning
- ☐ To ensure teachers are well informed of health information that could affect learning and behaviour at school
- ☐ Other: _____

10) What concerns do you as a teacher have with being able to access your students' health information? (tick all that apply)

- ☐ Unfairness if information has been shared but parent unable to access the information themselves
- ☐ Teacher not comfortable with accessing health information
- ☐ Teachers not trained to handle or access health information
- ☐ Labelling the student or whanau based on a diagnosis in their medical records
- ☐ Teachers are then required to act in a medical incident
- ☐ Some medical record information is sensitive/don't want all the information to be shared
- ☐ Parent can't control what information is shared
- ☐ This information is tapu and needs to be respected
- ☐ Parent cannot control who sees their child's health information
- ☐ Discrimination/disadvantaging the student
- ☐ Other: _____

11) What do you see being the benefits of sharing student health records with their teacher? (tick all that apply)

- ☐ Teacher will understand child's health background
- ☐ Teacher are to support the whole child, physically and emotionally
- ☐ Gives teachers immediate information when/if needed
- ☐ Helps explain learning concerns
- ☐ Teacher will know what to do in a health incident
- ☐ Able to ensure infectious illness is managed at school
- ☐ Teacher able to prevent child from getting unwell
- ☐ Teacher can adjust teaching to consider health concerns
- ☐ Other: _____

Study ID:

12) How much do you agree or disagree with the following statements?

	Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
The benefits and value of sharing health information outweigh the risks	1	2	3	4	5

Any final comments?

About You

Are you?	☐ Male ☐ Female ☐ Prefer not to say	
What year were you born?	_____	
What ethnic group do you belong to? (tick as many as apply):	☐ NZ European ☐ Pacific Islander ☐ Māori	☐ Asian ☐ Prefer not to say ☐ Other: _____
What best describes your role at your school? (please tick one)	☐ Kaiako ☐ Head Kaiako ☐ Pastoral Care Team	☐ Senior Management ☐ Other: _____
How many years have you been teaching?	_____	
What school do you work at?	_____	

Thank you for your responses!

Appendix D.2 – Kaiako Focus Group Consent, Information Sheet and Interview Schedule

School of Health Sciences
College of Education, Health and Human Development
University of Canterbury
Private Bag 4800
Christchurch, New Zealand

UNIVERSITY OF CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

Sharing health information with schools to enhance children's educational outcomes – What are your perceptions?
Consent Form for Focus Group

By signing below, you agree to participate in this research project and agree to the following points

- ☐ I have been given a full explanation of this project and have had the opportunity to ask questions.
- ☐ I understand what is required of me if I agree to take part in the research.
- ☐ I understand that participation is voluntary, and I may withdraw at any time without penalty. Withdrawal of participation will also include the withdrawal of any information I have provided should this remain practically achievable.
- ☐ I understand that any information or opinions I provide will be kept confidential to the researcher, Nikita Gregory, and that any published or reported results will not identify the participants. I understand that Nikita Gregory's supervisory team may have access to the research database, which has replaced my identifiable data with a study identification number. I understand that a thesis is a public document and will be available through the UC Library.
- ☐ I understand that to ensure the confidentially of other participants, I will treat other participants with confidentiality and not discuss the individuals who were at the focus group with others.
- ☐ I understand that all data collected for the study will be kept in locked and secure facilities and/or in password protected electronic form and will be destroyed after 10years.
- ☐ I understand that while anonymity cannot be provided, identifiable information will be confidential, and protected in password protected computers and locked filing cabinets only accessible by Nikita Gregory. I understand that study IDs will be allocated to further protect my information and any quotes published will use pseudonyms to ensure my confidentiality.
- ☐ I understand that I can contact the researcher, Nikita Gregory (nikita.gregory@pg.canterbury.ac.nz), supervisor team: Professor Philip Schluter (philip.schluter@canterbury.ac.nz), Professor Gail Gillon (gail.gillon@canterbury.ac.nz) andAssociate Professor Brigid McNeill (brigid.mcneill@canterbury.ac.nz) for further information. If I have any complaints, I can contact the Chair of the University of Canterbury Educational Research Human Ethics Committee, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nzI would like a summary of the results of the project.

Name:_____Signed:_____Date:_____

Email address *(for findings report)*:_____

School of Health Sciences
College of Education, Health and Human Development
University of Canterbury
Private Bag 4800
Christchurch, New Zealand

UNIVERSITY OF CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

Sharing health information with schools to enhance children's educational outcomes: What are your perceptions?
Information Sheet – Focus Group

My name is Nikita Gregory and I am a current doctoral student at the University of Canterbury – Te Whare Wānanga o Waitaha. I am looking into how sharing student health information will boost educational achievement and the concerns around sharing health information in this context.

The purpose of this study is to discover individuals' perceptions and beliefs around potentially sharing a student's health information with teachers and schools. There are two parts to this study. The first part is a questionnaire for parents and teachers asking about their concerns and beliefs around sharing student health information with schools. The second part is a follow up focus group, for teachers and parents, to discuss the themes that come from the questionnaire in an open environment. Participation for both parts of the study is optional and you are welcome to take part in none, one or both parts.

If you choose to take part in this study, you will be asked to participate in a focus group. These focus groups are estimated to last 60-90 minutes and will be held at your child's school. Snacks will be provided, and a small Koha will be given to show our appreciation of your involvement with the study.

Participation is voluntary, and you have the right to withdraw at any stage without penalty. You may ask for your raw data to be removed at any point. If you withdraw, we will do our best to remove all of the information relating to you from the research provided that this remains practically achievable.

The results of the project will be published, but please be assured of the complete confidentiality of data gathered in this investigation: your identity, or any information that may identify you, will not be made public. When compiled into a research database, each participant will be allocated a research identification number that will remove any personal details. Only Nikita Gregory (primary researcher) will be allowed access to your personal detail and corresponding study identification number for the ability to follow up with you if required. A transcription company, REV, may be employed to assist in the transcription and will be bound by strict confidentiality agreement. All information collected will be securely stored in a locked filing cabinet and on a password-protect computer that only Nikita Gregory (primary researcher) will have access to. If any quotes are used in the write up of the focus groups, then pseudonyms will be used to avoid identification. To ensure the confidentially of other participants, it is requested you treat their participation as confidential also. All information will be destroyed after a period of 10 years. Results from the information collected will form part of a doctoral thesis. A thesis is a public document and will be available through the UC Library.

Please indicate to the researcher on the consent form if you would like to receive a copy of the summary of results of the project. As a participant, you will also have the opportunity to review the transcript of the focus group you attended.

The project is being carried out by Nikita Gregory under the supervision of Professor Philip Schluter (philip.schluter@canterbury.ac.nz), Professor Gail Gillon (gail.gillon@canterbury.ac.nz) and Associate Professor Brigid McNeill (brigid.mcneill@canterbury.ac.nz). Any of the supervisors will be pleased to discuss any concerns you may have about participation in the project.

This project has been reviewed and approved by the University of Canterbury Educational Research Human Ethics Committee, and participants should address any complaints to The Chair, Educational Research Human Ethics Committee, University of Canterbury, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz).

Teachers focus group interview guide

Introduce yourself and why they the participants are here. Discuss how the FG is run. Explain that there are five points for discussion, each with an allocated 10 mins of free discussion and an extra 5 mins allocated for key points identified in the literature or Kaiako questionnaire that have not been discussed. Then a final 15 mins for final thoughts and comments. Go through of information sheet and consent form – get everyone to sign consent form. Give participants pseudonym to say before they start talking

On recording – Verbal Consent with each Pseudonym

Candidate Themes

- **Benefits of Sharing Student Health Information with Teachers**
  1) Safety

By sharing student health information, schools are able to use this information to make decisions that may prevent safety concerns (such as allergies, infectious disease) and better react to a health incident. Where can you see the benefits of sharing student health information impacting safety?

Key phrases/words for discussion:

- Preventative Safety
- Reactive Safety
- Immunisation Records

2) Teacher Awareness

How can you see student health information sharing impacting your day-to-day as a teacher?

Have you had any examples of how knowing about a child's health has change your practice?

Key phrases/words for discussion:

- Holistic Wellbeing
- In-classroom Support

- **Risks of Sharing Student Health Information with Teachers**

While the benefits are important, we also need to discuss the risks of sharing student health information. What are some of the risks of a system like this?

Key Phrases/words in discussion:

- Loss of Control
- Parental Responsibility
- Limitations Needed: (Types of information shared + who the information is shared with?)

What about solutions – are there any solutions that you can see that might work in overcoming these risks?

Key idea/s for discussion:

- Implementation considerations

- **Role of the Teacher**

I want to discuss the roles of the teacher now. According to the analysis done of the kaiako questionnaire there is debate about the roles of teachers, parents and schools.

What are the basic roles of a teacher when thinking about health in schools?

Have these roles changed? What are the new or added roles of the teacher?

Do the expectations of parents match these roles?

Key phrases/words for discussion:

- Providing holistic support
- In-classroom Support
- Safety: In school? Outside of School?
- Discussing concerns directly with parents

- **Role of the Parent**

What is the role of the parent in terms of their childs health? Has this role changed as it had for teachers?

Key Phrases/words in discussion:

- Control – parents need to have control as part of protection
- Inclusion – including parents in the discussion about their health, working with parents

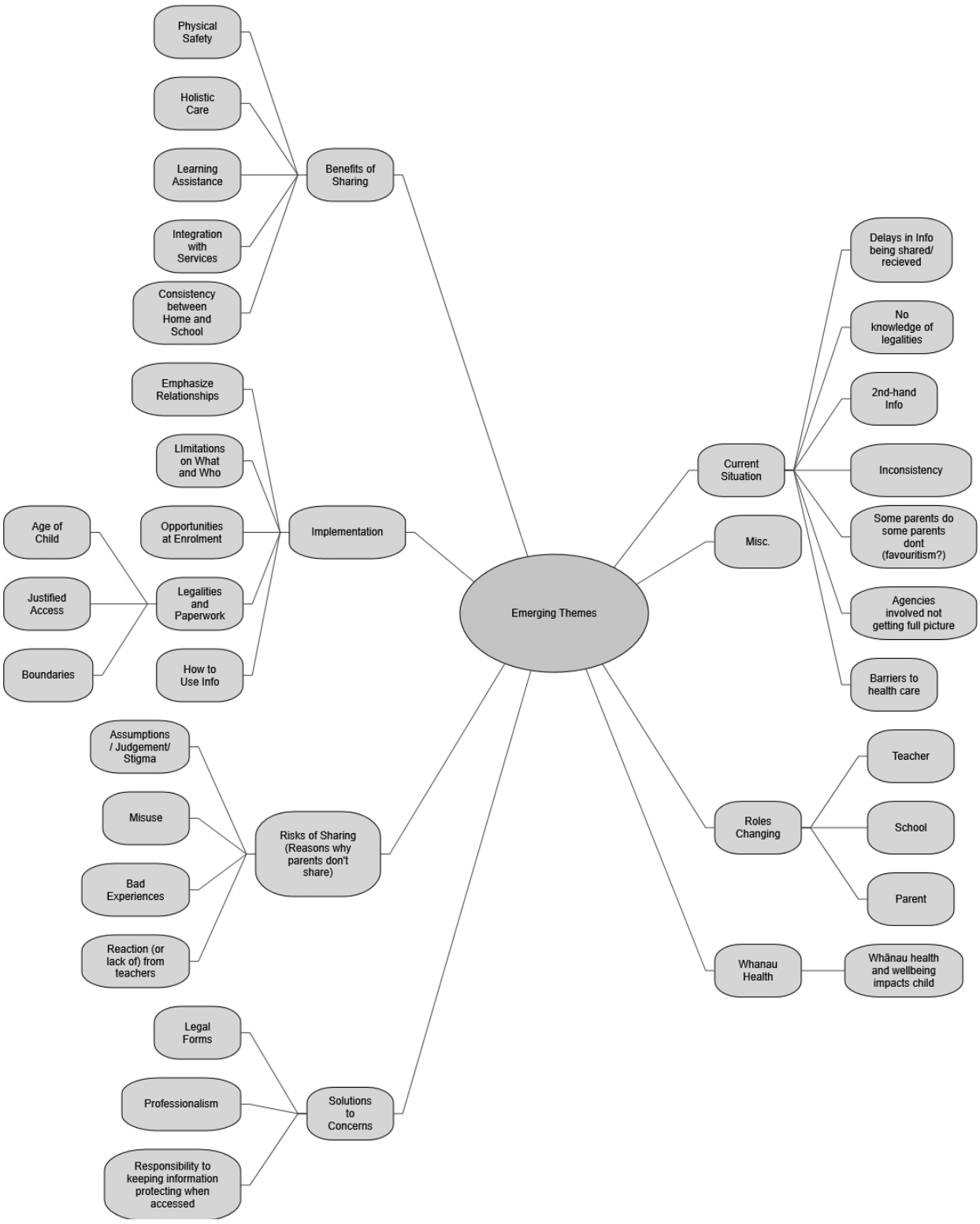
- **Role of the School**

How does the school fit in? What is their roles when thinking about student health?

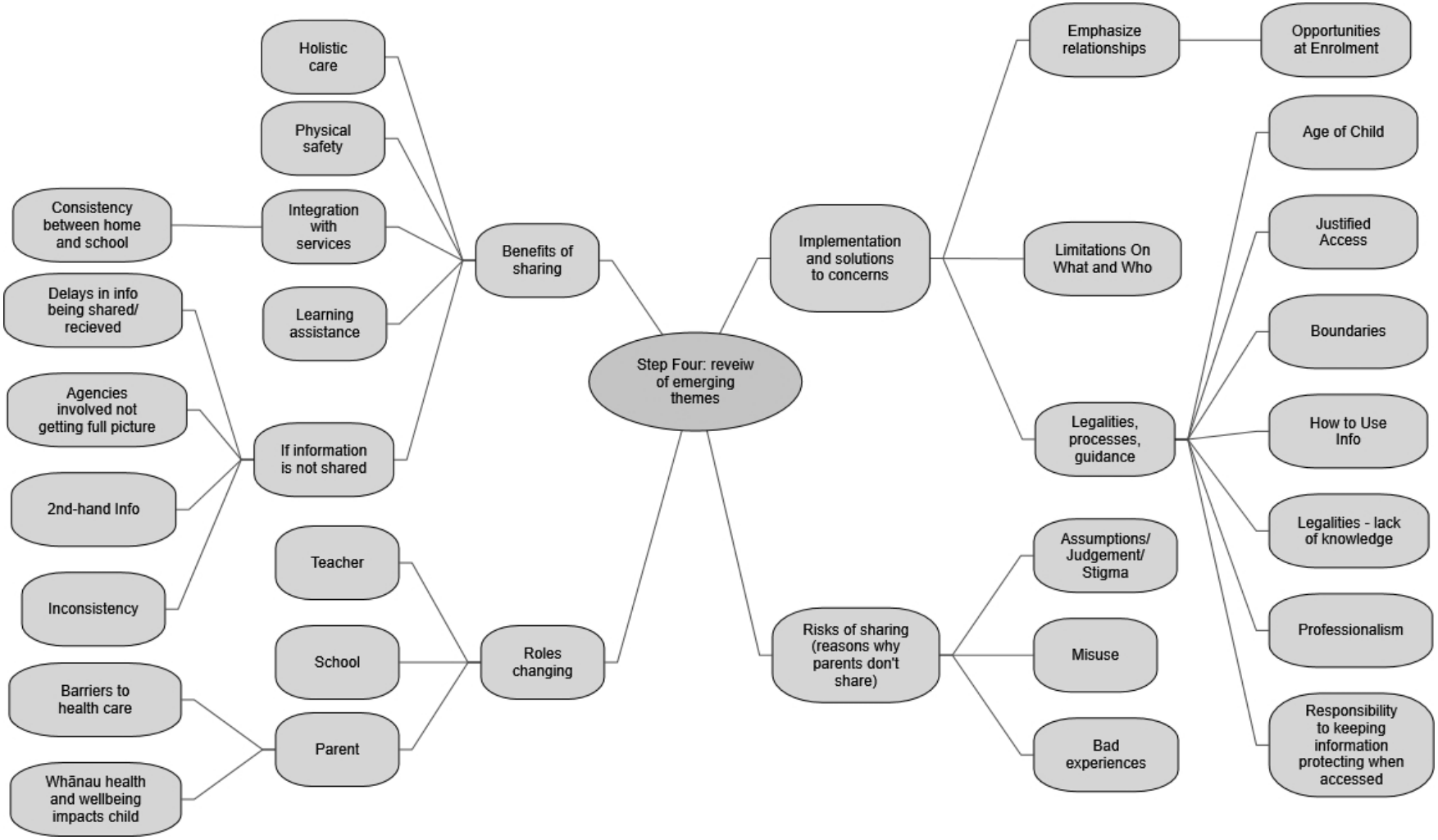
---

1) Probes Employed:
   a) Echo: Interviewer summarises participants point, encouraging the participant to develop the idea further, and clarify the point to other participants, encouraging discussion of the idea.
   b) Verbal agreement: interviewer gives the participant verbal agreement of their views using phrases such as, 'yes', 'okay', 'uh-huh'.
   c) Silent: By staying silent, the interviewer allows the participant to think out loud, and for other participants to probe and/or discuss the concept without verbal input from the interviewer.
2) Follow up questions:
   a) Tell me more about [idea]/could you tell me a little more about [idea] please?
   b) Why do you think you feel this way about [idea]?
   c) What did you learn from this experience? Has this experience influenced your views around health information sharing?
3) Key ideas (that go across questions)
   a) How is data currently shared in schools?
   b) How could a data sharing system work?
   c) How can any barriers be overcome?

Appendix D.3 – Step Three: Thematic Maps



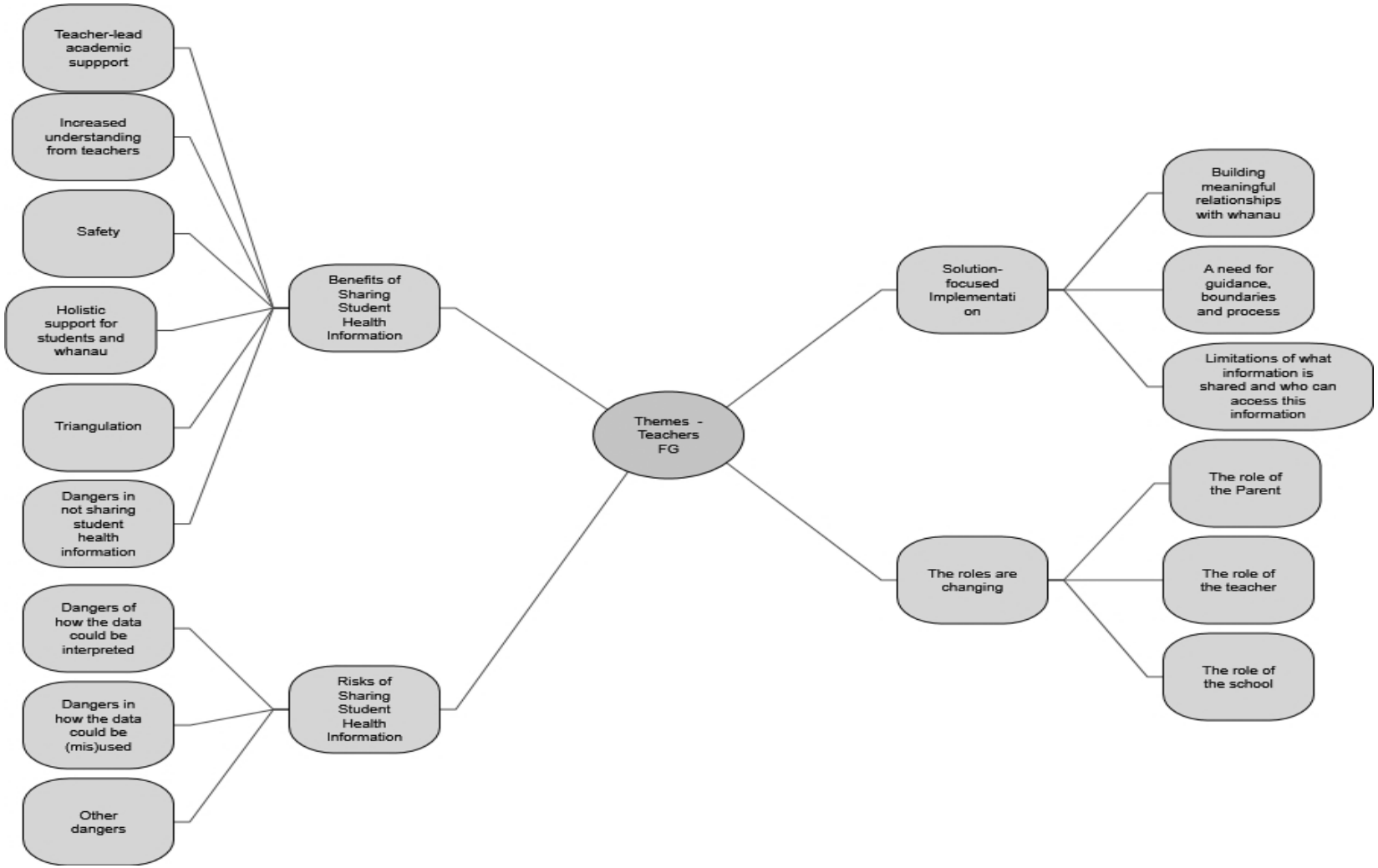
Appendix D.4 – Step Four: Thematic Maps



Appendix D.5 – Theme Definition

- Benefits of Sharing
    - Participants discussed the benefits of sharing student health information. A range of benefits were discussed, from ability for teachers to provide learning assistance to ensuring students are safe at school. This theme encompasses perceived direct benefits for teachers.
- Implementation
    - This theme considers how student health information could be shared though a digital platform in an ethical and considered way. It emphasises relationships with whānau, what information should be included, who should have access, how to use the information and creating clear processes that are legal and provide boundaries.
- Roles Changing
    - This theme is split into the role of the parent, the teacher and the school and considers what each of the roles include. This theme discusses the need for flexibility as the roles often overlap causing issues around understanding where the role starts and ends. It considers why parents are facing greater challenges in providing health care.
- Risks of Sharing (reasons why parents don't share)
    - Participants discussed their beliefs on why parents do not share health information and any risks that they could foresee in being a problem if health information was to be shared digitally.

Appendix D.6 – Step Five: Final Thematic Map



Appendix E – Phase Three Documents

Appendix E.1 – Parent Consent, Information Sheet and Questionnaire

Study ID:

School of Health Sciences
College of Education, Health and Human Development
University of Canterbury
Private Bag 4800
Christchurch, New Zealand

UC UNIVERSITY OF CANTERBURY
Te Whare Wānanga o Waitaha CHRISTCHURCH NEW ZEALAND

Sharing health information with schools to enhance children's educational outcomes
Consent Form for Questionnaire

Please sign below to indicate that you understand and agree with each statement:

- I have been given a full explanation of this project and have had the opportunity to ask questions.
- I understand what is required of me if I agree to take part in the research.
- I understand that participation is voluntary, and I may withdraw at any time without penalty. Withdrawal of participation will also include the withdrawal of any information I have provided should this remain practically achievable.
- I understand that any information or opinions I provide will be kept confidential to the researcher, Nikita Gregory, and that any published or reported results will not identify the participants or the involved school. I understand that Nikita Gregory's supervisory team may have access to the research database, which has replaced my identifiable data with a study identification number. I understand that the study findings will be presented in a thesis, which is a public document and will be available through the UC Library.
- I understand that all data collected for the study will be kept in locked and secure facilities and/or in password protected electronic form and will be destroyed after 10 years.
- I understand that while anonymity cannot be provided, all identifiable information will be treated confidentially, and protected in password protected computers and locked filing cabinets only accessible by Nikita Gregory. I understand that study IDs will be allocated to further protect my information.
- I understand that I can contact the researcher, Nikita Gregory (nikita.gregory@pg.canterbury.ac.nz), or her supervisory team: Professor Philip Schluter (philip.schluter@canterbury.ac.nz), Professor Gail Gillon (gail.gillon@canterbury.ac.nz) and Associate Professor Brigid McNeill (brigid.mcneill@canterbury.ac.nz) for further information. If I have any complaints, I can contact the Chair of the University of Canterbury Educational Research Human Ethics Committee, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz).
- By signing below, I agree to participate in this research project and understand the above statements.

*Name:*_____ *Signed:*_____ *Date:*_____

I would like to (please tick all that apply)

☐ Go into the draw to win $100 grocery voucher

☐ Be contacted via phone/email as a potential participant in a follow-up focus group related to this questionnaire (any participation in focus groups is voluntary, and every focus group participant will receive a small koha to show our appreciation for their time)

☐ Have a summary of the results emailed to me

If you have ticked any of the above, please provide an email or phone number for Nikita to get in touch

Email /phone number *(for $100 grocery voucher draw, report of findings and/or follow-up focus group)*:

_____

Please return this along with your questionnaire to your child's teacher or school staff member

Study ID:

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College of Education, Health and Human Development
University of Canterbury
Private Bag 4800
Christchurch, New Zealand

UNIVERSITY OF CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

Sharing health information with schools to enhance children's educational outcomes – What are your perceptions?
Information Sheet - Questionnaires

About the Study
The purpose of this study is to discover individuals' perceptions and beliefs around sharing a student's health information with teachers and schools. There are two parts to this study. The first part is a questionnaire for parents and teachers asking about their concerns and beliefs around sharing student health information with schools. Part Two is a follow up focus group, for teachers and parents, to discuss the themes that come from the questionnaire in an open environment.

Voluntary Participation, Commitment and Withdrawal
Participation for both parts of the study is optional and you are welcome to take part in none, one or both parts. If you do choose to participate in this part of study, you will be asked to complete a short questionnaire. The questionnaire is likely to take 10-15 minutes. Participation is voluntary, and you have the right to withdraw at any stage without penalty. You may ask for your raw data to be removed at any point and we will do our best to remove all of the information relating to you from the research provided that this remains practically achievable.

Confidentiality and Publishing
Any information or opinions you provide will be kept confidential to the researcher, Nikita Gregory, and that any published or reported results will not identify the participants or involved school. Nikita Gregory's supervisory team may have access to the research database, which will have any identifiable data replaced with a study identification number. Data collected for the study will be kept in locked and secure facilities and/or in password protected electronic form and will be destroyed after 10 years. While anonymity cannot be provided, identifiable information will be confidential, and protected in password protected computers and locked filing cabinets only accessible by Nikita Gregory.

Contact Details
You are welcome to contact Nikita Gregory (nikita.gregory@pg.canterbury.ac.nz), and the supervisory team: Professor Philip Schluter (philip.schluter@canterbury.ac.nz), Professor Gail Gillon (gail.gillon@canterbury.ac.nz) and Associate Professor Brigid McNeill (brigid.mcneill@canterbury.ac.nz) if you have any queries or comments relating to this research. This project has been reviewed and approved by the University of Canterbury Educational Research Human Ethics Committee and participants should address any complaints to The Chair, Educational Research Human Ethics Committee, University of Canterbury, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz).

If you agree to participate in the study, you are asked to complete the consent form and questionnaire, and return it via email to Nikita Gregory (nikita.gregory@pg.canterbury.ac.nz) or using the prepaid envelope provided. Alternatively, you are welcome to return it to your child's teacher.

Study ID:

Whānau/Parent/Family/Aiga/Caregiver Questionnaire

Tēnā koe; Talofa lava; Greetings to you. Thank you for agreeing to complete this questionnaire. We are very interested in your thoughts and opinions about sharing students' health information with teachers. **There are no wrong answers!**

For this research, medical/health records include diagnoses made by the doctor and referrals that the doctor has made and does not include GP notes or test results.

1) Is your child in year 0-2 at school? (please tick one)
   - ☐ Yes
   - ☐ No (If no, unfortunately at this time we are only looking at discussing the topic with parents of new entrance students. Thank you for your understanding)

2) What school does your child in year 0, 1 or 2 attend?
   _____

3) Do you think that a kaiako/teacher should have access to any of your tamaiti/child's health records? (please tick one)
   - ☐ Yes
   - ☐ No

   Please briefly explain your reason(s) for your choice: _____
   _____
   _____

4) Do you think that kaiako/teacher awareness about your tamaiti/child's health information is important to the teaching and learning that happens at school? (please tick one)
   - ☐ Yes
   - ☐ No

   Please briefly explain your reason(s) for your choice: _____
   _____
   _____

5) What health information would you feel comfortable allowing your child's teachers to access about your child? (tick all that apply)
   - ☐ Re-occurring illness (e.g. ear infections, colds)
   - ☐ Life threatening illnesses (e.g. severe allergies)
   - ☐ On-going medical conditions (e.g. asthma, diabetes)
   - ☐ Mental health (e.g. anxiety, depression)
   - ☐ Immunisation records
   - ☐ Hearing and visual health
   - ☐ Oral/Dental health
   - ☐ All medical and health records
   - ☐ None
   - ☐ No preference
   - ☐ Other: _____
     _____
     _____

Study ID:

6) Who would you feel comfortable accessing your child's health information? (tick all that apply)

- ☐ Principal of School
- ☐ Senior Management (Deputy Principal, Head of Year, Dean, Team Leader)
- ☐ Support Staff (Social Workers, Teacher Aides, Resource Teacher: Learning and Behaviour (RTLB), Counsellor)
- ☐ Child's classroom teacher
- ☐ Health Staff (Public Health Nurse, School Nurse)
- ☐ Teachers in child's year/team
- ☐ None
- ☐ No preference
- ☐ Other: _____

7) Whānau/family/caregiver consent for a kaiako/teacher to have access to a tamaiti/child's health records should be (please tick one):

- ☐ automatically given as part of the school enrolment process
- ☐ given only when a request has been made for health data to be released

Please briefly explain your reason(s) for your choice: _____

8) What role and/or responsibility does a parent have in sharing their child's health information with schools/teachers? (tick all that apply)

- ☐ To allow teachers access to health information that could concern the safety of others at school
- ☐ To ensure their child does not put other children at school at risk of infectious illness
- ☐ To ensure teachers have relevant health information regarding students with health concerns
- ☐ To allow teachers access to health information that could concern the child's learning
- ☐ To give consent for access to health information
- ☐ To limit who can access their child's health information
- ☐ To keep a child's health information between the whanau and the doctor
- ☐ To provide teachers with relevant health information
- ☐ Other: _____

9) What role/responsibility does a teacher have in managing a student's health and health information? (tick all that apply)

- ☐ To understand students' health backgrounds
- ☐ To know how to act in a medical incident
- ☐ To educate students with what health information is available to them
- ☐ To be fully aware of any student health concerns
- ☐ To provide emotional and social support when required
- ☐ To take on the role of a parent during school hours
- ☐ To ensure a students' private information is only shared with individuals on a need to know basis
- ☐ To discuss student health concerns with parents prior to providing support or teaching adjustments
- ☐ To adjust teaching according to students' health background
- ☐ To act on the parents' behalf when necessary
- ☐ Other: _____

Study ID:

10) What role/responsibility does a school have in managing a student's health and health information? (tick all that apply)

- ☐ To provide a safety environment for students
- ☐ To ensure parents are well informed of what sensitive information has been passed on to teachers
- ☐ To minimise infectious illness
- ☐ To ensure the school environment fosters learning
- ☐ To ensure teachers are well informed of health information that could affect learning and behaviour at school
- ☐ Other: _____

11) What concerns do you as a parent have with sharing your child's health information with their teacher? (tick all that apply)

- ☐ Unfairness if information has been shared but parent unable to access the information themselves
- ☐ Discrimination/disadvantaging the student
- ☐ Teachers not trusted to discuss medical information
- ☐ Labelling the student or whanau based on a diagnosis in their medical records
- ☐ Some medical record information is sensitive/don't want all the information to be shared
- ☐ Parent can't control what information is shared
- ☐ This information is tapu and needs to be respected
- ☐ Parent cannot control who sees child's health information
- ☐ Other: _____

12) What do you see being the benefits of sharing your child's health records with their teacher? (tick all that apply)

- ☐ Teacher will understand child's health background
- ☐ Teacher are to support the whole child, physically and emotionally
- ☐ Gives teachers immediate information when/if needed
- ☐ Helps explain learning concerns
- ☐ Teacher will know what to do in a health incident
- ☐ Able to ensure infectious illness is managed at school
- ☐ Teacher able to prevent child from getting unwell
- ☐ Teacher can adjust teaching to consider health concerns
- ☐ Other: _____

Study ID:

13) How much do you agree with the following statements?

	Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
The benefits and value of sharing health information outweigh the risks	1	2	3	4	5

Any final comments?

_____

_____

_____

_____

_____

About You

Are you?	☐ Male ☐ Female ☐ Prefer not to say	
What year were you born?	_____	
What ethnic group do you identify with? (tick all that apply):	☐ Māori ☐ Pacific Islander ☐ Asian	☐ NZ European/Pākehā ☐ Prefer not to say ☐ Other: _____
Highest education qualification (tick one):	☐ No qualifications ☐ Secondary school e.g. NCEA (Level 1-3)	☐ Post-Secondary Qualification (Level 4-10) ☐ Prefer not to say
What is your relationship to your child:	☐ Mother ☐ Father ☐ Whāngai/Foster parent	☐ Other whanau/family member ☐ Other: _____

Thank you for your responses!

Appendix E.2 – Newsletter Article for Participant Recruitment

Is your child in Year 0-2 at Ilam Primary?
Would you like to go into the draw to win $100 Grocery voucher?

Nikita Gregory along with the University of Canterbury is looking for parents of children in year 0-2 at Ilam Primary School to complete a 10-minute online questionnaire about perceptions of student health information sharing. All eligible participants go in to the draw to win a $100 Grocery voucher.
Here is a link to put in your browser to access the online version of the questionnaire along with information about the study and confidentiality:
www.tinyurl.com/y4omwzgd

If you would like a hard copy of the questionnaire please get in touch with Nikita on nikita.gregory@pg.canterbury.ac.nz or alternatively, ask your child's teacher.

Thank you and Good Luck!

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Appendix E.3 – Parent Focus Group Consent, Information Sheet and Interview Schedule

School of Health Sciences
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Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

Sharing health information with schools to enhance children's educational outcomes – What are your perceptions?
Consent Form for Focus Group

By signinf below you indicate that you understand each of the following points:

- ☐ I have been given a full explanation of this project and have had the opportunity to ask questions.
- ☐ I understand what is required of me if I agree to take part in the research.
- ☐ I understand that participation is voluntary, and I may withdraw at any time without penalty. Withdrawal of participation will also include the withdrawal of any information I have provided should this remain practically achievable.
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- ☐ I understand that to ensure the confidentially of other participants, I will treat other participants with confidentiality and not discuss the individuals who were at the focus group with others.
- ☐ I understand that all data collected for the study will be kept in locked and secure facilities and/or in password protected electronic form and will be destroyed after 10years.
- ☐ I understand that while anonymity cannot be provided, identifiable information will be confidential, and protected in password protected computers and locked filing cabinets only accessible by Nikita Gregory. I understand that study IDs will be allocated to further protect my information and any quotes published will use pseudonyms to ensure my confidentiality.
- ☐ I understand that the audio recording taken during the focus group may be transcribed by an transcription service, REV, and that this service follows appropriate guidelines that protect confidentiality.
- ☐ I understand that I can contact the researcher, Nikita Gregory (nikita.gregory@pg.canterbury.ac.nz), supervisor team: Professor Philip Schluter (philip.schluter@canterbury.ac.nz), Professor Gail Gillon (gail.gillon@canterbury.ac.nz) and Associate Professor Brigid McNeill (brigid.mcneill@canterbury.ac.nz) for further information. If I have any complaints, I can contact the Chair of the University of Canterbury Educational Research Human Ethics Committee, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nzI would like a summary of the results of the project.
- ☐ By signing below, I agree to participate in this research project.

Name:_____

Signed:_____

Date:_____

School of Health Sciences
College of Education, Health and Human Development
University of Canterbury
Private Bag 4800
Christchurch, New Zealand

UNIVERSITY OF CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

Sharing health information with schools to enhance children's educational outcomes: What are your perceptions?
Information Sheet – Focus Group

My name is Nikita Gregory and I am a current doctoral student at the University of Canterbury – Te Whare Wānanga o Waitaha. I am looking into how sharing student health information will boost educational achievement and the concerns around sharing health information in this context.

The purpose of this study is to discover individuals' perceptions and beliefs around potentially sharing a student's health information with teachers and schools. There are two parts to this study. The first part is a questionnaire for parents and teachers asking about their concerns and beliefs around sharing student health information with schools. The second part is a follow up focus group, for teachers and parents, to discuss the themes that come from the questionnaire in an open environment. Participation for both parts of the study is optional and you are welcome to take part in none, one or both parts.

If you choose to take part in this study, you will be asked to participate in a focus group. These focus groups are estimated to last 60-90 minutes and will be held at your child's school. Snacks will be provided, and a small Koha will be given to show our appreciation of your involvement with the study.

Participation is voluntary, and you have the right to withdraw at any stage without penalty. You may ask for your raw data to be removed at any point. If you withdraw, we will do our best to remove all of the information relating to you from the research provided that this remains practically achievable.

The results of the project will be published, but please be assured of the complete confidentiality of data gathered in this investigation: your identity, or any information that may identify you, will not be made public. When compiled into a research database, each participant will be allocated a research identification number that will remove any personal details. Only Nikita Gregory (primary researcher) will be allowed access to your personal detail and corresponding study identification number for the ability to follow up with you if required. A transcription company, REV, may be employed to assist in the transcription and will be bound by strict confidentiality agreement. All information collected will be securely stored in a locked filing cabinet and on a password-protect computer that only Nikita Gregory (primary researcher) will have access to. If any quotes are used in the write up of the focus groups, then pseudonyms will be used to avoid identification. To ensure the confidentially of other participants, it is requested you treat their participation as confidential also. All information will be destroyed after a period of 10 years. Results from the information collected will form part of a doctoral thesis. A thesis is a public document and will be available through the UC Library.

Please indicate to the researcher on the consent form if you would like to receive a copy of the summary of results of the project. As a participant, you will also have the opportunity to review the transcript of the focus group you attended.

The project is being carried out by Nikita Gregory under the supervision of Professor Philip Schluter (philip.schluter@canterbury.ac.nz), Professor Gail Gillon (gail.gillon@canterbury.ac.nz) and Associate Professor Brigid McNeill (brigid.mcneill@canterbury.ac.nz). Any of the supervisors will be pleased to discuss any concerns you may have about participation in the project.

This project has been reviewed and approved by the University of Canterbury Educational Research Human Ethics Committee, and participants should address any complaints to The Chair, Educational Research Human Ethics Committee, University of Canterbury, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz).

Parents focus group interview guide

Go through of information sheet and consent form – get everyone to sign consent form.

Introduce yourself and why they the participants are here. Ask participants to choose an assigned pseudonym for the audio recording and write up.

RECORDING ON

Discuss how the FG is run. Explain that there are five points for discussion, each with an allocated 10 mins of free discussion and an extra 5 mins allocated for key points identified in the literature or parents questionnaire that have not been discussed. Then a final 15 mins for final thoughts and comments.

On recording – Verbal Consent with each Pseudonym

Candidate Themes

- **Benefits of Sharing Student Health Information with Teachers**

  Preliminary results – PQ (Benefits)

What are some of the benefits of sharing student health information with schools and teachers from your POV?

Key phrases/words for discussion:

- Safety
  - Preventative Safety
  - Reactive Safety
- Immunisation Records
- Teacher Awareness
  - Holistic Wellbeing
  - In-classroom Support

Asthma Example:

Mia is 5-year-old new entrance student, who is struggling to catch her breath. If teachers were able to look Mia's medical notes up on a system, what could be the benefits of this? What about the risks? Are there any Solutions to these risks?

Have you had any experiences of the benefits of sharing health information?

- **Risks of Sharing Student Health Information with Teachers**

  Preliminary results – PQ (Concerns)

While the benefits are important, we also need to discuss the risks of sharing student health information. What are some of the risks of a system like this?

Key Phrases/words in discussion:

- Loss of Control
- Parental Responsibility
- Limitations Needed: (Types of information shared + who the information is shared with?)

What about solutions – are there any solutions that you can see that might work in overcoming these risks?

- Building Relationship
- Communication between agencies

Diabetes/ADHD Example:

Alex is 5-year-old new entrance student, who often acts up in class and loses concentration. His teacher is wondering whether there may be a physical reason for his behavior. What should Alex's teacher do? If teachers were able to look Alex's medical notes up on a system, what could be the benefits of this? What about the risks? Are there any Solutions to these risks?

- **Role of the Teacher**

I want to discuss the roles of the teacher now. According to the analysis done of the both the teacher and parent questionnaire there is debate about the roles of teachers, parents and schools.

Preliminary results – PQ (Teacher Roles)

What are the basic roles of a teacher when thinking about student health in schools?

Have these roles changed? What are the new or added roles of the teacher?

Key phrases/words for discussion:

- Providing holistic support
- In-classroom/Practical Support
- Safety: In school? Outside of School?
- Discussing concerns directly with parents
- Duty of Care – guardian/act on parent behalf

- **Role of the Parent**
  - Preliminary results – PQ (Parent Roles)

What is the role of the parent in terms of their child's health? Has this role changed?

Key Phrases/words in discussion:

- Control – parents need to have control as part of protection; how far does that protection go? Are there situations where that control is given up?
- Inclusion – including parents in the discussion about their health, working with parents, relationship building
- Consent – what does that look like? opt in/out? Verbal/written?

- **Role of the School**

Preliminary results – PQ (School Roles)

How does the school fit in? What is their roles when thinking about student health?

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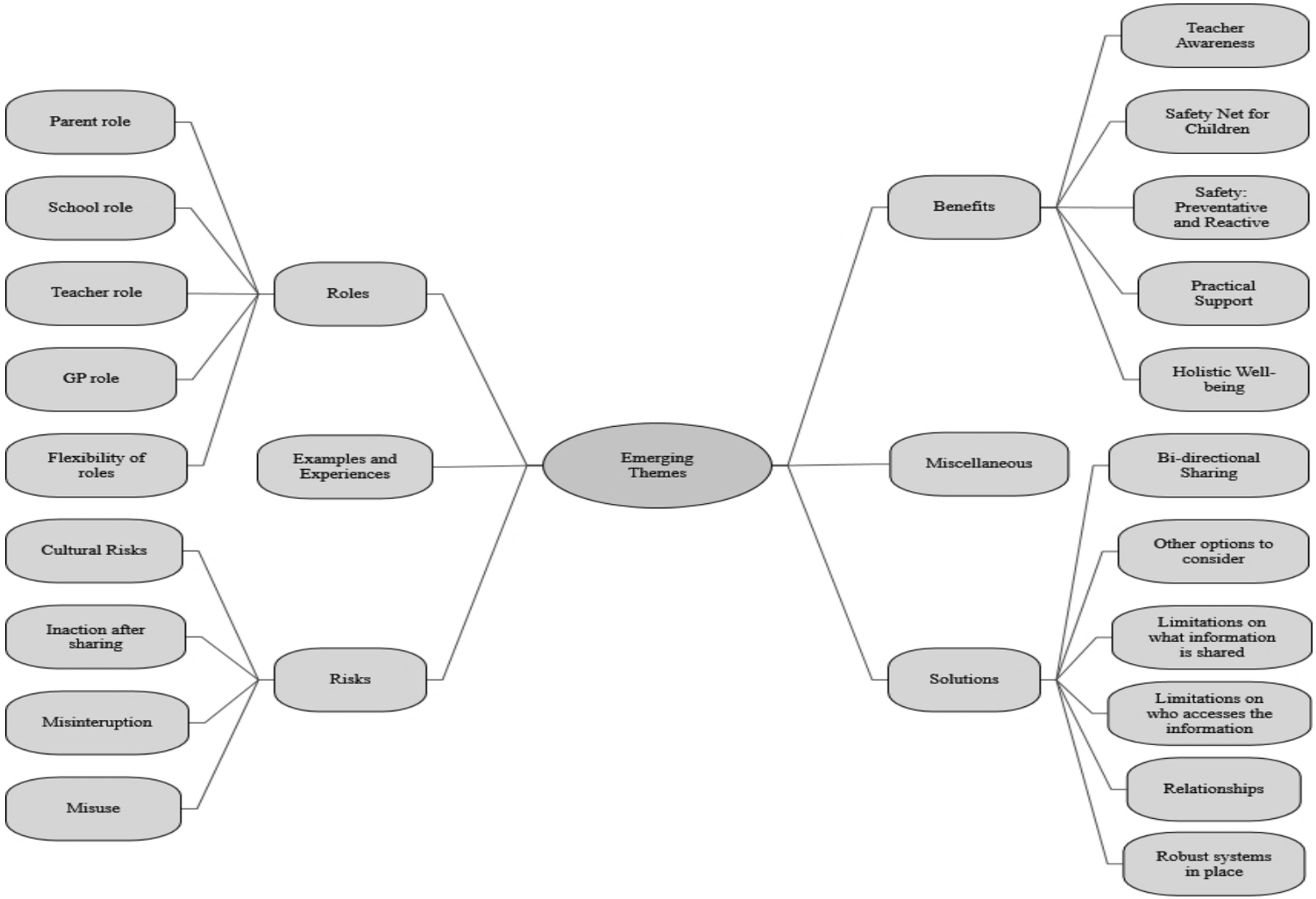
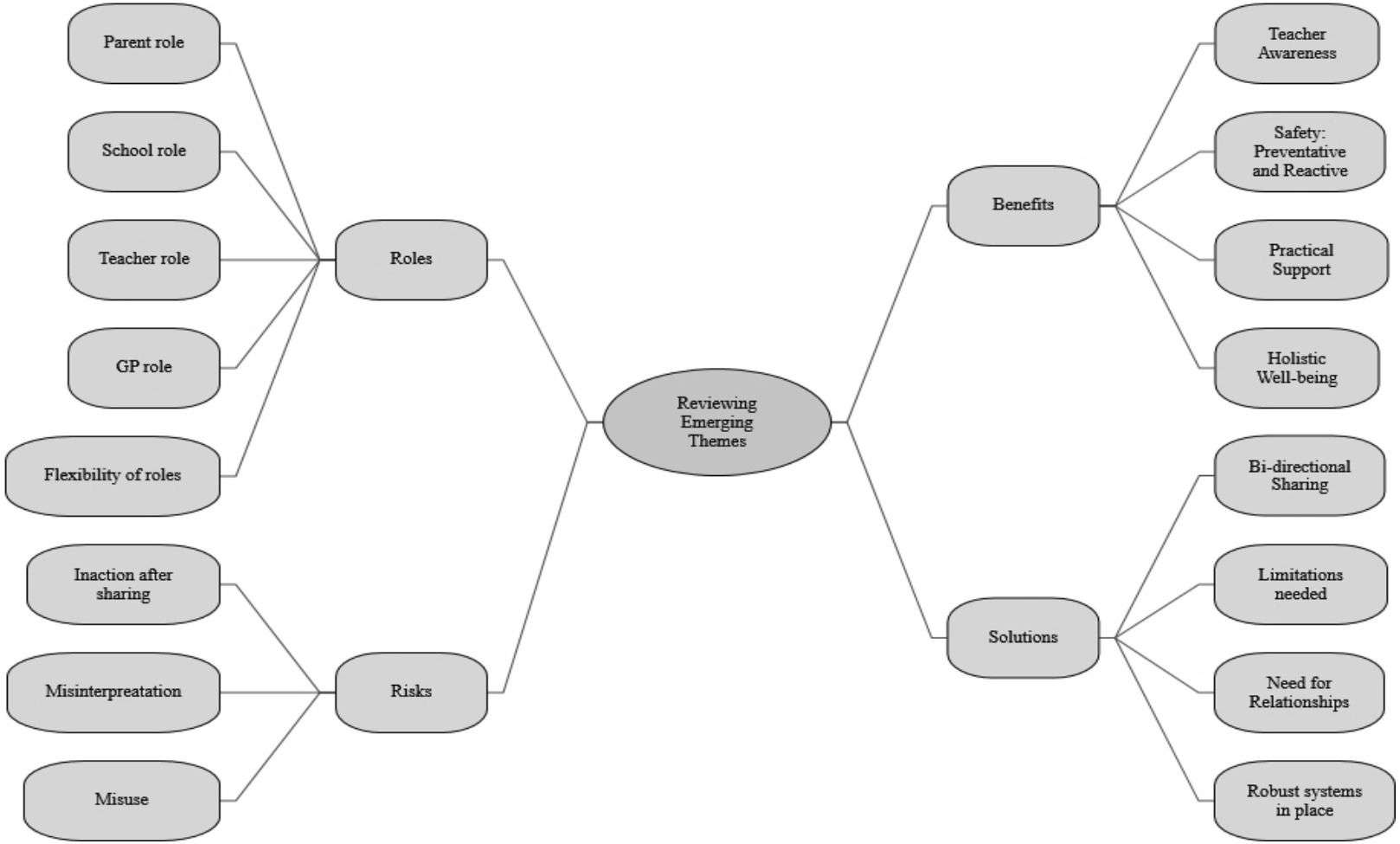
1) Probes Employed:
   a) Echo: Interviewer summarises participants point, encouraging the participant to develop the idea further, and clarify the point to other participants, encouraging discussion of the idea.
   b) Verbal agreement: interviewer gives the participant verbal agreement of their views using phrases such as, 'yes', 'okay', 'uh-huh'.
   c) Silent: By staying silent, the interviewer allows the participant to think out loud, and for other participants to probe and/or discuss the concept without verbal input from the interviewer.
2) Follow up questions:
   a) Tell me more about [idea]/could you tell me a little more about [idea] please?
   b) Why do you think you feel this way about [idea]?
   c) What did you learn from this experience? Has this experience influenced your views around health information sharing?

Appendix E.4 – Step Three: Thematic Maps



Appendix E.5 – Step Four: Thematic Maps



Appendix E.6 – Theme Definition

- Roles – Parent/Teacher/GP/School
    - This theme discusses the roles of teacher, schools and parents. The role of the GP considered with particular focus on how GP's could help parents understand their children's health. Participants also discussed how GP's could contribute to a digital health information sharing system.
- Risks – Dangers of misuse and misinterpretation/Resourcing issues
    - The risks theme considers the adverse outcomes that could come about from sharing student health information. It includes cultural sensitivities, misuse and misinterpretation of the data.
- Benefits – Safety/Ability to provide tailored support
    - The benefits talk about how people could all be positively influenced by health information sharing if done correctly. It considers the potential of the data-sharing system that bridges the gap between health and education.
- Solutions – justified access and traffic light approach/relationships with whānau/clear policies
    - Participants considered the risks of a health information sharing and begun developing solutions to a system that might mitigate, overcome or minimise these risks. These ideas included discussion about resourcing, policies and limitations as well as potential design features.

Appendix E.7 – Step Five: Final Thematic Map